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Caring for Children with Severe Cerebral Palsy: The Lived Experience of Parents

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We hereby certify that this dissertation, submitted by Jason Cook, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the dissertation requirement for the degree of Doctor of Philosophy in Physical Therapy.

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Abstract

The purpose of this study is to explore the lived experience of parents who care for their child with cerebral palsy who function at Gross Motor Function Classification System (GMFCS) Level V. Additionally, the study also explores the parent's understandings and beliefs about pain and non-pain related emotional distress, and the meaning of caring, providing care, and providing comfort for their child with GMFCS Level V cerebral palsy. The study was conducted using a qualitative, hermeneutic phenomenology approach with semi-structured interviews and participant-initiated journaling. The study included 11 participants who are caregiving parents of their child with GMFCS Level V cerebral palsy. Data were collected using audio-recorders, field notes, and journals. Audio recordings were transcribed and data were analyzed using the constant comparison method.

Four themes emerged from the analysis: (1) Life is hard, heavy with burden, worry, and love; (2) Remarkable; (3) Identity transformation and empowerment towards authenticity; and (4) Living a life that is planned, forced with structure and without spontaneity. Findings from this study bring to light the participants' experience of care which manifests through worry, love, and duty. Parents are able to differentiate pain from emotional distress by observing and learning to communicate with their child. Parents believe that communicating with their child requires patience, sensitivity, time, awareness of the child's experiences, and is essential for their child to experience well-being.

Understanding gained from this study includes an awareness of self-efficacy that evolves in parents who care for their child with severe forms of cerebral palsy, the importance in providing family-centered-care, and a conceptual exploration of the physical therapists experience in using developmental tact in the care of the pediatric population.

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Chapter 1: Introduction

Cerebral palsy is a non-progressive disorder of the central nervous system, caused by either abnormal development or injury to the brain during early perinatal development.[1,2] Cerebral palsy is often comprised of multiple disorders because of its variability in both cause and presentation.[3] Previous research has focused on creating a classification system for cerebral palsy because of the high variability seen in its presentation. The Gross Motor Function Classification System (GMFCS)[4] is a highly researched and widely utilized scale that classifies individuals ages 2-18 years with cerebral palsy based on their motor function and level of independence with certain tasks including sitting, standing, and walking.[4,5] Children who are independent with all mobility tasks and present with the least amount of functional limitations are classified as GMFCS Level I.[5] Children who present with the most severe forms of cerebral palsy and are fully dependent for all mobility tasks including maintaining an upright posture are classified as GMFCS Level V.[5]

Children with GMFCS Level V cerebral palsy are more prone to medical complications due to the severity of their condition, some of which can be painful.[6,7] Common medical conditions that these children face include a greater need for feeding tubes and an increased risk for developing respiratory problems.[6] Children who function at a GMFCS Level V also have a greater risk of hip displacement in childhood.[7] In a 2013 study, it was found that musculoskeletal pain is directly linked to severity of

cerebral palsy, and those children who function at a GMFCS Level V are at greater risk of experiencing musculoskeletal pain with greater duration, intensity, and frequency.[8] Children classified as Level V also present with severe motor impairment, atypical motor patterns, and in many cases, may also have severe communication impairments.[3,9] These individuals may lack the ability to express when they are in pain, the severity of that pain, or if they are experiencing emotional distress because of a limited ability to communicate.[9] Emotional distress includes feelings of fear, worry, sadness, depression, and anxiety,[10] and is associated with higher levels of chronic pain in children and adolescents.[11]

Pain and emotional distress may limit the ability of parents and children with severe cerebral palsy to attend social events and interact within their environment.[12,13] Additionally, emotional distress signals disguised as pain related behaviors may lead to utilization of pain medications. In a study of children with cerebral palsy who presented with all GMFCS levels, at least 20% of the sample had utilized pain medications within the past 2 weeks, and many of them used more than one type of pain medication.[14] Often the side-effects of narcotic-based pain medications can cause drowsiness, impaired cognitive function, and impaired bowel function including constipation.[15] If a child is misinterpreted as having pain when they are really experiencing non-pain related emotional distress, they may be given pain medications that may impair his/her ability to participate in social activities. This potential misunderstanding of the underlying issues could lead to a missed opportunity of engagement and understanding of that child's needs beyond those related to pain. Being able to achieve a state of well-being and comfort not

only comes from the management of pain, but for many it also comes from the management of distress.[16]

Measuring pain in children who are unable to communicate about their pain can be difficult. Many pain scales that are used for children with severe communication impairment use descriptors of typically observed pain behaviors.[17] Physical therapists use observational pain scales to evaluate pain in individuals with GMFCS Level V cerebral palsy.[17] These pain scales are based on activities observed in human movement that are associated with pain. Monitoring and distinguishing pain from non-pain related emotional distress in children with severe forms of cerebral palsy can be challenging because of their atypical motor presentations and limited communication skills. The combination of these two factors may impact a caregiver's ability to distinguish pain from emotional distress in these individuals.

A systematic review performed by Ring and Cook[18] determined that scales validated for use in children who have GMFCS Level V cerebral palsy included the Pediatric Pain Profile[19] and Pain Evaluation Scale.[18,20] These pain scales do not differentiate behaviors associated with pain and non-pain related emotional distress.[20] While determining the presence and severity of pain is important, it is also important to understand the presence of non-pain related emotional distress in children with severe cerebral palsy. Distinguishing pain from non-pain related emotional distress has not been studied in this population.

Current research on pain and distress in the population of children with severe forms of cerebral palsy focuses exclusively on pain.[17,18,20,21] Physical therapists have

been shown to be reliable proxies in recognizing pain in individuals with cerebral palsy.[22] The research available on understanding non-pain related emotional distress in this population is extremely limited.[23] The ability to understand and distinguish between pain and emotional distress in children with severe forms of cerebral palsy is important because pain and emotional distress can impact quality of relationships, motivation to participate and interact in social situations, and overall quality of life.[13] Additionally, treatment for pain and emotional distress may actually be different in this population.

Life may be stressful for parents who care for their child with cerebral palsy.[24] This can especially be difficult when their child is experiencing pain or emotional distress and is unable to communicate.[24] There is limited understanding of the experience of caring for children with severe cerebral palsy from the perspective of parents.[13,24,25] Parenting a child with cerebral palsy may impact the quality of life of the parent. [13,25] Some parents experience physical issues due to the effects of caring for a child with cerebral palsy including loss of sleep, and fatigue associated with the physical labor required for mobilizing a dependent child.[13] Parents may also experience psychological distress, especially when the parent does not feel that they have sufficient support to help care for their child.[26] Caregivers of children with cerebral palsy may also be less likely to have a job due to the care and time required for their special needs child, even as their child nears the age of typical pre-adult autonomy.[26] Understanding the experiences of parents, and the meaning these experiences have for them, will help physical therapists provide a more informed, and effective approach to family-centered care. Research has reported that parents and siblings of children with severe cerebral palsy may also be impacted.[27,28] Parents may struggle with caring for a child with severe forms of cerebral

palsy, especially when their child exhibits challenging behaviors.[29] Because of the complex relationship between pain and emotional distress,[11] parents often seek insight from a team of specialists including a physical therapist to help better understand their child's pain and distress. When a child is unable to communicate their pain or emotional distress, the observed behaviors can be misinterpreted. Parents consult physical therapists because of their knowledge of the musculoskeletal and neuromuscular systems, and their role in identifying and relieving pain in children with cerebral palsy.[22] Therefore, the exploration of understanding the experiences of parents, including when parents care for their child during pain and non-pain related emotional distress in children with severe forms of cerebral palsy, is relevant to physical therapy practice. Physical therapists may be called upon to relieve pain,[22] however, they are also charged with helping a family discover their child's potential so that within a family-centered approach, the child can participate in life enhancing roles.[30, 31] Family-centered care is a model of care delivery in which the health care team empowers the family with the care of their child.[32] By understanding the experience of parents, physical therapists are better able to determine a family's needs, establish realistic goals and develop strategies for more effective family education and training for the care of their child. A review of the literature revealed 18 studies that looked at experiences related to parents of children with cerebral palsy, however, all of these studies focused on parental emotional distress.[12,13,24-29,33-39,40,41] In addition, only two of these articles were qualitative studies.[13,25] Therefore, research literature is limited in understanding the lived experience of parents of children with GMFCS Level V cerebral palsy and how parents recognize and distinguish pain behaviors from emotional distress behaviors. Such research will provide a foundation for

filling this gap, and contribute to family-centered care and pediatric physical therapy practice.

Problem Statement and Goal

There is little evidence available regarding the experience of caring for a child with GMFCS Level V cerebral palsy from the perspective of parents, nor their understanding and ability to distinguish pain from emotional distress during the care of their child.

The purpose of this study is two-fold:

1) to understand and describe the experience of parents who care for children with GMCS Level V cerebral palsy
2) to understand these parents' perceptions and beliefs about identifying and managing pain and non-pain related emotional distress.

Relevance and Significance of the Study

The family-centered care model of care delivery has been shown to demonstrate improved outcomes in service delivery for children with special health care needs.[32] Within the family-centered care delivery model, health care providers are encouraged to partner with the family in the care of the special needs child and to be empathetic to the lifeworld of the family.[42] Knowledge gained through understanding the lifeworld of parents during the care of their children with cerebral palsy can inform family-centered

care in physical therapy. More specifically, improved understanding of how parents experience and manage care for their child's pain and non-pain related emotional distress will enable physical therapists to develop effective strategies for parent education and training.

Physical therapists and other healthcare professionals could benefit from understanding parent's experiences to provide further education for new parents of children with cerebral palsy, and other health care professionals to enhance family-centered care and family empowerment of care in this population.

Research Questions

1) What is the lived experience of parents who are caring for their child with severe cerebral palsy?
2) What are the parent's understandings and beliefs about pain and non-pain related emotional distress?
3) What is the meaning of caring, providing care, and providing comfort to a child with severe cerebral palsy?

Definition of Terms

The following is a list of terms and the definitions that will be used for each term throughout this study.

Pain: The term "pain" will be used throughout this document to mean physical or bodily suffering associated with some form of disorder or injury,[43] unless otherwise noted with further explanation provided.

Emotional Distress: The term emotional distress is concerned with the type of distress associated with the psychological, social, and spiritual aspects of life that are non-physical in nature.[10] Emotional distress is comprised of various states of emotion or 'bad feelings' including fear, worry, sadness, depression, anxiety, isolation, or even spirituality or existential crisis.[10]

Parent or Parents: Parent(s) refers to the parent participants in this study.

Severe Cerebral Palsy: The term severe cerebral palsy will be defined in this study as those individuals with cerebral palsy who function at a GMFCS Level V.

Summary

Children with severe forms of cerebral palsy often experience pain and discomfort. These children may also also have a limited ability to communicate their wants and needs. Pain and non-pain related emotional distress are parts of the human condition. As humans, we often find ways to manage our pain and emotional distress. Children with severe cerebral palsy may have a limited ability to manage their own pain and emotional distress and rely on caregivers and health care providers to adequately help them during times of pain and emotional distress. There have been few studies to examine the experience of providing care to these children. This study seeks to understand and describe the experience of parents who care for children with GMCS Level V cerebral palsy, and to understand

their perceptions and beliefs about identifying and managing pain and non-pain related emotional distress.

Chapter 2: Review of the Literature

Introduction

Within this chapter, foundational concepts related to cerebral palsy, family-centered care, the Theory of Human Caring, Comfort Theory, and the International Classification of Functioning, Disability and Health Model will be presented. This chapter will provide theoretical support for the purposes of this study: to understand and describe the experiences of parents who are caring for children with cerebral palsy who function at GMFCS Level V, and to understand their perceptions and beliefs about managing pain and non-pain related emotional distress.

Cerebral Palsy

History of Cerebral Palsy

Dr. John Little first identified cerebral palsy in the 19th Century.[44] In the review of his own patients' medical histories, he observed that many children who acquired deformities during their life, also had cognitive impairments. Further, these patients' had often suffered periods of asphyxia after birth. A discrepancy that remained following his discovery was that many children who experienced asphyxia immediately following birth did not have ongoing birth defects.[44]

The term *cerebral palsies* however was coined by William Osler in 1889, who also believed that the debilitating condition was caused primarily from trauma to the

brain.[44] The diagnostic term *cerebral palsy* was first coined by the famous psychoanalyst Sigmund Freud.[44, 45] He hypothesized that because many children who experienced asphyxia at birth had no defects later in life, that there may be a deeper underlying cause of their disability.[44] Further studies that occurred in the 20th century also found that while a subset of children's signs of cerebral palsy could be linked to birth asphyxia, a growing prevalence of neurological birth defects could not be linked to a history of asphyxia at birth and therefore must be associated with other complications of the developing fetus or infant.[45]

Etiology of Cerebral Palsy

While some evidence supports that birth asphyxia, also referred to as perinatal events,[46] continues to be a sizeable cause of cerebral palsy, additional research points to other causes as being more prevalent. In Sweden, the most recent data suggest birthing related injuries such as birth asphyxia, accounts for around 46% (n= 195) of the cases of cerebral palsy,[46] while in Australia it is only 13% (n=251).[47] Either way, this leaves a sizeable amount of the population of children who have cerebral palsy due to other causes. As medical science advances, so too does our understanding of the causes of cerebral palsy.[45] Genetic variation is observed in many cases of cerebral palsy.[48] In a recent study investigating whole genome sequence mapping, 14% (n=183) of individuals with cerebral palsy were identified as having a gene-causing variant.[48] In Norway, a 2014 study shows that first degree relatives have a 6 to 9 fold increased risk in also having cerebral palsy, correlating a genetic association with cerebral palsy.[49]

A systematic review found that of the preconceptual factors that are related to cerebral palsy, parental intellectual disability, thyroid dysfunction (both hyper- and hypo-thyroidism), and a maternal history of a seizure disorder are highly associated with a diagnosis of cerebral palsy.[50] Other preconception factors include a prior history of maternal stillbirth or miscarriage, low socioeconomic status, being a child of parents who are African American living in the United States, being a child of Australian Aboriginal descent, or maternal age over 40 years at birth.[50]

Antenatal maternal factors associated with cerebral palsy include maternal obesity,[51] incompetent cervix, seizure disorders, maternal cardiac or respiratory disease, abnormal amniotic fluid amounts, meconium aspiration or meconium stained amniotic fluid, bleeding in the second or third trimester, hypertension, pre-eclampsia, and chorioamnionitis or infection of the fetal membranes.[50] Additionally, children who are born small for their gestational age are also at an increased risk for cerebral palsy.[50] Neonate-specific risk factors for cerebral palsy include asphyxia, seizures after birth, hypoglycemia, respiratory distress, infection, and jaundice.[50]

Cerebral palsy may also be acquired postnatally often as a result of cerebral trauma that occurs from an infection or injury sustained after birth.[52] Trauma associated with motor vehicle accidents, child abuse, and near drowning also can lead to cerebral palsy.[52] Infectious diseases such as septicemia, malaria, and meningitis are significant causes of postnatally acquired cerebral palsy in developing countries.[52]

Definition and Diagnosis of Cerebral Palsy

Cerebral palsy is a disorder that presents itself through clinical findings and is often diagnosed before the age of 5.[47] To diagnose a child with cerebral palsy, two of the following criteria must be met[1]:

1) The child has a delay in motor skills where their motor quotient is at or below 70 (out of 100);

2) The child has atypical tone, atypical deep tendon reflexes, or incoordination of movement;

3) The child presents with atypical primitive reflexes, positive support reflexes, tonic labyrinthine reflexes, or postural reactions.[1]

Researchers find that the term cerebral palsy is a heterogeneous diagnosis and its lack of homogeneity could lead to potential error when studying the population.[53] However, some caregivers believe that maintaining cerebral palsy as a heterogeneous group helps caregivers plan for the broader diagnostic category for the purposes of diagnosis, patient management, and for supporting access to life enhancing services.[54] Therefore, the most recently adopted definition is:

"Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of

sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems." [55Pg.6]

This definition is distinguishable from previous definitions in many ways. It specifies that the developmental disability associated with cerebral palsy must include disorders of movement and posture.[1] Therefore, developmental disorders that do not present with deficits of posture or movement do not fit the diagnosis of cerebral palsy.

Cerebral palsy is also considered a non-progressive disorder of the central nervous system where the mode of injury is not continuous and does not lead to further brain lesions.[1,56] Even though the primary brain lesion does not progress or worsen, the symptoms do change over time due to the developing maturation of the human body with an impaired movement and postural support system.[56,57] Throughout the natural history of the condition of cerebral palsy, individuals with cerebral palsy may go through periods of both improvement and deterioration of clinical presentation.[57]

Classification of Cerebral Palsy

The history of attempting to describe and classify cerebral palsy over the past century is vast.[1] Some classifications focus on the topographical classification system of hemiplegia, double hemiplegia, diplegia, tetraplegia, quadriplegia[1] and monoplegia.[58] Other classfications involve descriptions of movement disorders including spastic, flaccid, mixed, ataxic, athetoid, dyskinetic, hypotonia, and hypertonia.[1,59] Both of these types of classification structures will be explored in the following paragraphs.

The Swedish Classification System was created by a group of researchers in Sweden who produced a method of classifying the variability in cerebral palsy through clinical description.[57] This includes a topographical description of hemiplegia (where one side of the body is more greatly impacted by movement impairments), diplegia (where both lower extremities are most greatly impacted by the movement impairment), and tetraplegia (where all parts of the body are impacted by movement impairments).[57] An advantage of this classification system is its simplicity,[55,57] as well as its ability to describe body segments affected by cerebral palsy. One limitation is that topographical presentation is not always consistent from one person to another, especially when attempting to differentiate diplegia from tetraplegia.[57] Individuals with cerebral palsy may have variability in motor presentation because of the varying nature of the etiology associated with cerebral palsy, the varying levels of healing from traumatic injuries, and individual differences.

Another classification system that was introduced in the 1980's was created in an attempt to standardize the language associated with describing and recording the clinical signs of cerebral palsy.[57] A meeting was held by Evans et al[59] to discuss ways to describe the observed motor behaviors in individuals with cerebral palsy.[59] This group created a classification system with the following associated definitions for each of the following terms:[59]

- *Hypotonia* is described as having a reduced tone in the muscles, also described as "floppy tone".[59]
- *Hypertonia* is described as having excessive stiffness as well as atypical or abnormal posturing during attempted voluntary movement.[59]

- *Spasticity* is indicated as a "clasp-knife" movement with an increase in muscle tone when a passive stretch is applied to the muscle.[59]
- *Rigidity* is described as a lead-pipe stiffness in the muscle tissue.[59]
- *Dyskinesia* is a fluctuation in muscle tone with involuntary movement or posturing during times of muscle rest. Dyskinesia is also exacerbated during times of emotion elevation.[59]
- *Ataxia* is described as having postural instability or incoordination of the limbs during purposeful movements.[59]

These classification structures have helped create homogeneous groups of individuals with cerebral palsy, allowing some distinguishable characteristics between the different forms of cerebral palsy.[57] While both topographical and movement descriptors are beneficial in describing different characteristics of cerebral palsy, they do not distinguish between those individuals with cerebral palsy who do and do not require medical and assistive services for their care. In addition, they do not define the overall functional skill level of the individual with cerebral palsy.[56] This can make it more difficult to determine the level of assistance and care that an individual with cerebral palsy will require.

The Gross Motor Function Classification System (GMFCS) was first published in 1997 as a tool to classify cerebral palsy based on the disability and functional limitations presented by each child.[4] With cerebral palsy being a complex and often unspecified disorder, this system of classification was established as a way to characterize the primary impact of the disorder based on the functional capabilities of the individual in

both sitting and walking.[4, 55] In 2002, Rosenbaum and colleagues[60] determined the GMFCS to be a reliable measure for predicting long term functional outcomes and prognostication of gross motor functional skills in young children with cerebral palsy.[60] In 2007, the authors published the GMFCS- Expanded and Revised GMFCS (GMFCS - E&R); expanded to include individuals 12 to 18 years of age and revised to include activities that impact the daily life skills of the individual.[5] The authors also emphasized the importance of using the tool as a measure of an individual's typical motor function in daily life rather than on a child's gross motor capacity.[5]

The GMFCS E&R is comprised of 5 different levels.[5] (See Table 2.1: Gross Motor Function Classification System) GMFCS Level I is defined as being an individual with cerebral palsy who is ambulatory, does not require an assistive device, and does not have limitations with mobility. GMFCS Level II is defined as being an individual who is ambulatory with some limitations including difficulty walking longer distances, or who may require the use of a hand held assistive device.[5] These individuals may choose to use wheeled mobility for long distances. The individual at a GMFCS Level III classification is characterized as being somebody who walks with a handheld mobility device for short distances, and of all of the GMFCS levels, demonstrates the greatest variety in terms of using mobility for longer distances outdoors and in the community; including use of self-propelling and powered mobility wheelchairs.[5] These individuals require the use of physical assistance or a support surface to move through the transition of sit to stand, and they also may require sitting support with a seat belt for alignment and balance support. Individuals at GMFCS Level IV are individuals who require the use of a wheeled mobility device for functional mobility.[5] They are capable of using powered mobility, but

may be transported in a manual wheelchair during times when a powered wheelchair is not available or not able to be used. Adaptations are necessary to participate in physical or sports related activities. Individuals classified as GMFCS Level V require assistance for all functional mobility and require the use of a wheelchair for all transportation needs.[5] They have significant difficulty with postural corrections and difficulty maintaining an upright posture against gravity. They require assistance of 1-2 caregivers, and possibly a mechanical lift to transition from one surface to another. If this individual utilizes powered mobility, they often require additional seating and positioning, as well as control adaptations.[5]

Table 2.1: Gross Motor Function Classification System Summarized [5]

Level	Description
I	Children are independent and move without limitations.
II	Child walk, however, they have some limitations.
III	Child walks with assistive device. May utilize wheeled mobility for longer distances. May require physical assistance for more demanding tasks.
IV	Children requires wheeled mobility, either manual or power, for most settings. Adaptive seating required for postural support.
V	Children are dependent for mobility requiring a manual wheelchair, and requires adaptive equipment for postural support and head control.

The GMFCS has been reported to be a good prognostication tool for determining the long term functional performance of an individual with cerebral palsy.[60] Utilizing the Gross Motor Function Measure (GMFM)[61], the GMFCS predicts that children who are a GMFCS Level I, II, III, IV, and V will achieve 90% of their maximum GMFM score by the age of 4.8 (4.4 - 5.2 95% Confidence Interval (CI)), 4.4 (3.5 - 5.0 95% CI), 3.7 (3.2 - 4.3 95% CI), 3.5 (3.2 - 4.0 95% CI), and 2.7 (2.0 - 3.7 95% CI) years of age, respectively.[60]

Population at GMFCS Level V

Impairments of Body Function associated with GMFCS Level V Cerebral Palsy

There may be many medical and functional complications associated with a diagnosis of cerebral palsy due to the associated neurological impairment and secondary issues associated with a lack of typical mobility of the body. Children with cerebral palsy who function at a GMFCS Level V present with severe motor control deficits. Children with cerebral palsy at a GMFCS Level V are more likely to experience complications surrounding constipation, and while many children take medication to address this issue, it is often not treated to resolution.[62] Seizure activity is also a frequent co-morbidity in this population.[56] Approximately 43% of children who function at GMFCS Level V experience seizures, with the most having a generalized seizure disorder of the central nervous system.[63] Other frequently occurring complications include, but are not limited to, communication deficits, bone mineralization deficits due to a lack of typical weight bearing activity and nutritional deficits, bony malformation, scoliosis, muscular

contractures, abnormal muscle tone and spasticity, urinary incontinence, abnormal sensory perception, hearing and vision impairments, poor oral-motor skills with reliance on tube feeding, and issues associated with impaired cognitive functioning.[64,65]

Children who function at a GMFCS Level V are the most likely of individuals with cerebral palsy to be at risk for structural bony malformations that are painful, including hip dysplasia.[7] Many children who have hip malformation including hip dysplasia also have hip pain.[66] When left untreated, it is estimated that 25-50% of those with hip dysplasia experience ongoing pain.[66]

Experiences of Pain in GMFCS Level V Population

Parental perceptions are often utilized to investigate issues regarding pain in individuals with severe forms of cerebral palsy.[67] Sources of pain in this population are multifactorial and dependent on the complications that each individual is experiencing. Families perceive pain being caused from multiple conditions.[14,21,67] Children who have gastrostomy tubes and those receiving medication for gastrointestinal issues are often perceived by parents as having more pain than children who do not have these factors.[67] Gastro-esophageal reflux, gut motility issues, and constipation are all frequently associated with pain.[21] Additional associated sources of pain in children with cerebral palsy include pulmonary disorders, musculoskeletal disorders including joint pain, hip subluxation,[14,21] muscle spasm,[14,21] back pain associated with decreased or impaired mobility[21] and muscle contracture,[14] hip subluxation and dislocation.[14] In addition, children with severe cerebral palsy can have pain associated with poor supportive and adaptive equipment, including wheelchair seating and positioning, orthotics, and hand

splints.[21] In addition, children with cerebral palsy may also experience situational pain common to the childhood experience (i.e., ear aches, toothaches during development, etc.).[21]

Parents of children with severe cerebral palsy perceive pain by observing behavioral changes in their child including facial grimacing and facial posturing, changes in body movement, vocal sounds of pain including crying and moaning, as well as observable physiological changes including increased perspiration and changes in skin color associated with signs of physiological distress.[21] Health providers use observational pain scales to evaluate pain in children with GMFCS Level V cerebral palsy.[17] These pain scales are often validated using infants in the neonatal intensive care unit, or are based on facial grimacing, crying, gross motor movements, changes in motor states, and changes in motor behaviors of children with severe motor and cognitive impairments.[67] Some examples of observational pain scales include the Faces, Legs, Activity, Cry, and Consolability Scale (FLACC),[68] Pediatric Pain Profile,[19] the Non-Communicating Children's Pain Checklist,[69] and the Pain Evaluation Scale[19,20,70] Health care providers utilize the FLACC scale as a method of quickly identifying pain behaviors associated with the five key characteristics of the scale.[71] The Pediatric Pain Profile is an interview style pain profile of caregivers' perceptions that uses a qualitative interviewing process to determine pain behaviors in individuals with severe neurological impairments.[72] The Pain Evaluation Scale is a 22-item scale that scores the parents perceived pain of the child based on the items within the scale.[20] These pain scales focus on pain behaviors and do not differentiate pain behaviors from behaviors associated with emotional distress.[20] Parent perceived quality of life scales have also been used to evaluate pain in children

who are non-verbal with cerebral palsy.[73] Jayanth et al[73] found that physiotherapy stretching and toileting were perceived by parents as causing their children the greatest pain.[73] However, researchers in this study mention that the behaviors parents associated with pain could also be signs of a child's discomfort or displeasure and may not necessarily be associated with pain.[73]

In the population of children who have severe forms of cerebral palsy, health care providers turn to pain medication to help alleviate these children of their symptoms associated with pain.[14,74] However, when medications are provided on an as needed basis to children with severe communication or cognitive impairments, there is concern that children may be under or over-treated for pain.[74] Pain medications that can be used to address pain in this population have many unwanted side effects including sedation, decreased respiration, drowsiness, paradoxical agitation, constipation, blurred vision, hallucinogenic dysphoria, hypotension, and other systemic effects.[74] Providing pain medication may help reduce pain when children are experiencing pain; however, over-treating pain can lead to negative consequences. Although parent report is generally a good indicator of a child's pain, it has been reported that there are some instances in which parents overestimate their child's pain, especially when it is post-surgical.[75] In addition, children with severe cognitive and motor impairments may present with behaviors such as atypical facial movements, atypical vocalizations that may sound like moaning or grunting, and atypical gross motor behavior of tension in the muscles that may or may not be indicative of pain.[76] If parents or caregivers misperceive these behaviors as pain, pain medications may be given in error leading to the over-treatment

of pain,[76] and the under acknowledgement of other issues that could be causing the atypical motor behaviors in the child, including emotional distress.

Communication Deficits in GMFCS V Population

It is often difficult for health care providers to distinguish pain from emotional distress in children with GMFCS Level V cerebral palsy. Children with severe cerebral palsy often have impairments associated with speech, communication,[9] swallowing,[9] and cognitive functioning.[77] Individuals who present with a more pronounced motor impairment have a greater risk of having a more significantly impaired ability to communicate, and those with GMFCS Level V cerebral palsy are at risk of being misunderstood due to the severe communication impairments often present with this condition.[9] Furthermore, having a learning disability is strongly associated with the level of activity limitations present in cerebral palsy.[77] Therefore, children with GMFCS Level V cerebral palsy are the most likely to also have a combination of learning disabilities, cognitive impairments and communication deficits[9,77] that may further impact their ability to express their thoughts, wants, needs, pleasures, displeasures, and pain.

The Communication Function Classification System (CFCS) is a validated tool for use in individuals with cerebral palsy to describe the varying functional communication abilities in this population.[78] The CFCS classifies individuals with cerebral palsy based on their ability to send and receive information effectively to other individuals, and classifies individual on a 5 level scale.[78] An individual who is classified with a CFCS Level I is described as being able to effectively and efficiently communicate by sending and receiving information with both familiar and unfamiliar individuals.[78] A

person who is classified with a CFCS Level V is seldom able to send or receive communication effectively, even with familiar individuals.[78] (See Table 2.2: Communication Function Classification System) The levels of the CFCS are moderately correlated with those of the GMFCS.[79] Children with GMFCS Level V are more likely to have issues with communication due to the breakdown during the communication process.[79] A breakdown in communication is not always due to the limitations of the individual with cerebral palsy.[80] For instance, a caregiver may be the source of a communication breakdown by ignoring a physical sign of communication, also known as non-verbal communication.[81] While non-verbal modes of communication are a method to assist this population with communication, this method can be limiting.[81] Non-verbal communication is heavily dependent on the caregiver's receptiveness to communicate in alternative manners,[81] openness to actively seek out how to communicate with the individual with severe cerebral palsy, and overall ability to be able to understand the individual.[82] Often, those responsible for caring for children with severe forms of cerebral palsy rely heavily on the child's family to understand their physical, social, and emotional needs.[82] While caregivers, including nurses and therapists, are educated in cerebral palsy, many have little to no education in complex communications needs.[82] Therefore, families and health care providers may find it difficult to determine when a child with cerebral palsy is exhibiting behaviors of pain or emotional distress due to missing subtle communication cues indicative of these behaviors.

Table 2.2: Communication Function Classification System Summarized[78]

Level	Description
I	Child sends and receives with both familiar and unfamiliar people effectively and efficiently
II	Sends and recieves with both famliliar and unfamiliar people but extra time is required
III	Sends and receives with familiar people effectively, but not with unfamiliar people
IV	Inconsistently sends and receives with familiar people
V	Seldom sends or receives, even with familiar people

Decreasing Pain and Improving Function through Seating and Positioning

Physical therapists work as a part of the health care team to address the physical needs of mobility and function and help children with GMFCS Level V cerebral palsy achieve their greatest potential to participate in life enhancing roles through a holistic, family-centered approach to care.[83,30,84] When individuals with GMFCS Level V cerebral palsy appear to be in pain or discomfort, physical therapists are often sought to help the family and child find comfort from physical pain. Positioning and repositioning through the use of various pieces of supportive equipment are often used as a method for trying to improve comfort, reduce pain, and improve function in children with severe cerebral palsy.[85,86]

Adaptive seating is specialized and customized supportive seating that both supports posture and assists with postural control.[87] Physical therapists use adaptive seating and positioning equipment to encourage functional participation.[85] Adaptive seating can improve upper extremity function for activity participation and can assist an individual in participation by supporting the body in a manner that facilitates activity.[88] Further, postural alignment and supportive positioning can have a positive impact on swallowing skills, mitigating the risk of aspirating food in children with severe cerebral palsy who receive their nutrition orally.[89] Aspiration can have serious deleterious effects on lung functioning over a lifetime, impacting other areas associated with an individual's health status and quality of life.

Adaptive seating and positioning are also used as a means to achieve greater comfort during passive mobility within the home and community. Adaptive seating and

positioning can alter muscle tone during sitting in children with cerebral palsy.[90] In some children, altering the body's orientation from an upright, fully vertical sitting position to a position of a 30 degree tilt back in space, may cause changes in both back extensor and hip adductor muscle activity. Yet, some children may present with increased back extensor and hip adductor muscle tone when placed in the reclined position as compared to the upright position.[90] Muscle tone can have an impact on an individual's physical comfort, especially when the individual lacks the motor ability to alter their body position and self-relieve muscle tension through active range of motion and mobility.

Adaptive seating and positioning can impact postural alignment. Adaptive seating utilizing a 3-point lever system, where padding and supportive structures are strategically applied to the seating system to support an upright sitting posture, has been shown to improve the static postural alignment over a system with similar height lateral supports, with a more even distribution across the supporting pads.[91] However, the pressure applied to the skin in the support pads is larger in the 3-point support system compared to the lateral support pads.[91] Weighing the benefit of having improved postural alignment over the detriment of having excessive forces applied to the skin could impact the individuals perception of comfort associated with seating and positioning. When addressing issues of deformity, immobility, and the associated risk of pressure ulceration, the adaptive seating system can be viewed as an extension of an orthosis by providing support, and distributing pressure to minimize the risk of ischemia on the integumentary system, therefore reducing the risk of skin breakdown from excessive pressure.[86] However, these devices may also cause discomfort in children with GMFCS Level V cerebral palsy due to the excessive forces that may be required to achieve good postural alignment.[21]

Seating and positioning can have an impact on an individual's respiratory function.[92] Adaptive seating, when providing postural support, can increase vital capacity, forced expiratory volume in one second (FEV1) and expiratory time.[92] This change, in part, is due to the support of the spine and ribcage, allowing for greater expansion of the lungs during breathing, regardless if the postural deficits are due to flexible or fixed structural deformities.[92] Therefore, altering the seating and positioning system to improve respiratory function can have a varying effect on an individual's pain and non-pain related distress associated with limited respiratory capacity.

Positional support for children with severe forms of cerebral palsy often extends beyond the function of sitting. Postural management programs are interventions for individuals with severe movement impairments that provide postural support throughout an individual's daily activities.[93] Supportive equipment, including adaptive seating devices, standing frames, bed supports, orthosis, and splints are used in a postural management program to support the body, prevent, and correct deformities, and enhance participation. However, research is limited regarding the effectiveness of these postural management programs in meeting these goals.[93]

A systematic review exploring dosing of pediatric standing frame use determined that utilizing standing frames in individuals with cerebral palsy may have a positive effect on bone mineralization.[94] Another systematic review found that utilizing standing programs may have benefits associated with improving bone mineralization, reducing hypertonicity and spasticity, and improving range of motion (ROM); however, more empirical research was recommended.[95] Another study looking at the impact of utilizing standing frames with the legs placed in an abducted and extended position found that one

hour of daily standing can reduce the progression of hip migration and dysplasia in children with cerebral palsy.[96]

Bed positioning is also a method associated with postural management programs. A pilot study examining hip abduction systems used in the lying position has the potential to improve hip alignment and decrease hip migration percentage; however, half of the sample population were unable to complete the program due to difficulties sleeping.[97] Altering the nighttime sleep position in postural support systems; however, has the potential for both improving, and worsening oxygen saturation in children with cerebral palsy[98] and may make it more difficult for some children to sleep.[97] This is dependent on each individual's specific needs for postural correction and response to the postural correction.[98]

While positioning equipment with children with cerebral palsy may provide benefits to the body systems, the overall amount of correction for postural support is often greater in individuals with greater deficits, especially those with a GMFCS Level of V.[93] Larger corrective forces have the potential to cause discomfort in children with severe forms of cerebral palsy.[93] In contrast, a lack of postural support can also lead to greater amounts of discomfort due to continuous muscle tightening, spasming, and pain associated with deformities.

Families and other health care providers seek the assistance of physical therapists for providing children with GMFCS Level V cerebral palsy a plan for postural support that improve or maintain alignment and enhances comfort. Health care professionals often utilize adaptive equipment to support these individuals in functional participation.[85]

However, this might not be enough. Seeking corrective forces for postural alignment may be beneficial to a childs' overall health; however, during the implementation process, physical therapists should also consider how best to utilize adaptive equipment to support the childs comfort and well-being. To promote comfort that may allow increased participation in this population, physical therapists must also seek to understand the holistic needs of the individual.[99]

Family Centered Care and Addressing Emotional Distress

Family-centered care is an approach to patient management where the family is a vital component to the care of the patient.[32] It is a philosophy in which health care providers, the family, and the patient are all members of a team, and each member is treated with dignity and respect.[84] In the family-centered care approach, the team builds on the strengths of the family to empower them to better support and care for their child with special health care needs.[84] When family-centered care is delivered, the outcomes of that care should focus beyond the physical needs of the child to include the emotional, social, and cognitive needs of the child as well as the parental and family needs.[100] This includes parent satisfaction, family reduction of stress and worry, and sibling related outcomes to enhance the experience of the family unit.[100] Physical therapists are a part of the provider team for children with cerebral palsy GMFCS Level V. It is important that physical therapists understand and support the many dimensions of the human experiences within family-centered care to support and empower the family unit.

Parenting a child with developmental disabilities, including cerebral palsy, can lead to a fluctuating load of distress as the child moves through different stages within

their lifecycle.[38] While the majority of parents who have children with cerebral palsy adapt to the diagnosis,[101] it is more likely for parents of children with more severe cerebral palsy to struggle with depression, family dysfunction, marital problems, and health-related quality of life issues.[27,101] Greater motor impairment in children with cerebral palsy is a factor that has been shown to indicate greater levels of parental distress.[38,27] Additionally, maladaptive behaviors of the child with severe cerebral palsy have also been considered as a variant for increased parental distress.[102] When the cause of cerebral palsy is due to a perinatal stroke, the mother is more likely to feel symptoms of guilt and anxiety when compared to the father.[27] A Canadian study examining health related outcomes of caregiving parents of children with cerebral palsy showed that these parents, when compared to a typical population, had greater incidence of distress and chronic distress, as well as greater issues with pain including back problems, migraines, intestinal ulcers, arthritis, and other health related conditions including asthma.[35] One theory as to why this may occur is the increased demands and stressors associated with caring for a dependent child.[35]

Of children with cerebral palsy, those classified with GMFCS Level V are the most likely to experience pain.[6-8] Measuring pain in this population can be difficult because it is based on observing behaviors that are assumed by the caregiver to be related to pain.[17] Atypical motor presentation and a decreased ability to communicate can make it difficult to distinguish pain related behaviors from emotional distress. Healthcare providers are in a position to look beyond the experiences of pain to empower families to support their child's social, emotional, and cognitive needs.

Distress is a construct that is often difficult to capture. Distress has been non-exclusively associated with conditions of depression and anxiety.[103] However, the idea of distress has also been described as being both correlated to, and in opposition of, psychological well-being.[103] The American Cancer Society defines distress as "unpleasant feelings that may cause problems as you cope with cancer and it's treatment".[104] The National Research Council (US) Committee on Recognition and Alleviation of Distress in Laboratory Animals describes distress as being an "aversive, negative state" or existence where an organisms "coping and adaptation processes fail to return an organism to physiological and/or psychological homeostasis".[105] Experiencing a state of distress can be due to either acute or chronic disturbances in the organism.[105]

Because distress can come from both physiological and psychological factors, distinguishing between distress and pain in children with severe cerebral palsy can be difficult. The term emotional distress, however, is more focused and denotes the type of distress associated with the psychological, social, and spiritual aspects of care that are non-physical in nature.[10] Emotional distress is comprised of various states of emotion or 'bad feelings' including fear, worry, sadness, depression, anxiety, isolation, or even spirituality or 'existential crisis'.[10 p344] Within populations of individuals who are unable to communicate about their pain and emotional distress, it is insufficient to only focus on pain reduction.[106] It has been suggested that within these populations, life without pain is not equal to a life lived in comfort.[106] It has also been suggested when considering distress and pain, comfort should be the ultimate goal of effective care, and that comfort "is achieved by easing and relieving distress".[107 p173]

The term emotional distress encapsulates the distinguishable concepts between pain and distress under investigation in this study. However, the more ambiguous term "distress" is often used in the literature surrounding the care of people who have difficulty with communication. There is limited research in the investigation of distress in populations of individuals who have impaired communication abilities; however, one population in which distress has been recognized and reported is in individuals with Alzheimer's disease. Distress is a common factor observed in patients who have Alzheimer's disease.[108] In a large study utilizing data from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) Zhou et al[108] found that medical interventions, and the deterioration associated with the disease process, was positively correlated with increased levels of distress in individuals with Alzheimer's disease.[108] This population has more medical examinations during times when the disease process is progressive.[108] In addition, these patients often take medications that impact the central nervous system.[108] Individuals with Alzheimer's disease who utilized less nursing services for assistance were also more likely to experience distress.[108] In addition, there was a positive correlation between patient distress and caregiver distress.[108] This is not an uncommon caregiver experience.[108,109] In a study evaluating the quality of life and pain in children with cerebral palsy,[110] parent distress was negatively associated with the parent-proxy reporting of quality of life in children with cerebral palsy, meaning that parental feelings of distress were associated with parental perceptions of lower quality of life for the child with cerebral palsy.[110]

Theories of Caring and Comfort

When the goals of patient care shift from removing pathology to enhancing well-being, the outcomes of the human experience also shift from removing pathology to enabling and supporting well-being.[111,112] This drive for change is supported in the World Health Organizations International Classification of Functioning, Disability, and Health (ICF) in which health care providers seek to identify factors that influence an individual's quality of life rather than solely focusing on ameliorating impairments that result from a health condition.[30] Theories associated with enhancing care and patient well-being are limited, however, two theories have emerged: (1), the Theory of Human Caring, and (2) Comfort Theory.

Theory of Human Caring

Jean Eaton founded the Theory of Human Caring in the late 1970's as she began to explore the concepts of caring beyond the actions that are typically considered to be what she refers to as "curative factors."[113] She was attempting to explain the part of nursing that engages with the patient to compliment the therapeutic interactions of the medical team and support the patient throughout his or her time in the caring environment. The Theory of Human Caring, although grounded in nursing practice, has been described as both a discipline specific and a transdisciplinary model of caring in health care.[113]

Within the Theory of Human Caring, health care providers have a moral and ethical responsibility to care for people within a global community.[113] Caring, in health care, is an intentional action on the part of the health care provider. The Theory of

Human Caring supports the concept that there is both an art and a science when caring for another human being in health care.[113] The theory offers a framework consisting of *10 Carative Factors* that unify the health care provider and the patient within a global community of common health related goals.[113] (see Table 2.3: 10 Carative Factors)

Table 2.3: 10 Carative Factors [180]

“

1) Formation of a humanistic-altruistic system of values
2) Instillation of faith-hope
3) Cultivation of sensitivity to one’s self and to others.
4) Development of a helping-trusting, human caring relationship.
5) Promotion and acceptance of the expression of positive and negative feelings.
6) Systematic use of a creative problem-solving caring process.
7) Promotion of transpersonal teaching-learning.
8) Provision for supportive, protective, and/or corrective mental, physical, societal, and spiritual environment.
9) Assistance with gratification of human needs.
10) Allowance for existential-phenomenological-spiritual forces. ” 180 (p 131-132)

Care research is essential to the field of nursing because of the impact it has on perceptions of the discipline and the delivery of care.[99] Other health related disciplines also play a major role in the care of patients. As such, the Theory of Human Caring is applicable to a more global community of health care providers.

Comfort Theory

When considering goals associated with the care of children with severe cerebral palsy, one significant goal may be to provide comfort. One established framework of comfort in the field of nursing is Kolcaba's Theory of Comfort.[99] The Theory of Comfort is a theoretical framework and a holistic approach to providing relief in the context of an individual's physical, psychospiritual, sociocultural, and environmental features of the human experience.[99]

Comfort Theory has distinguishable characteristics that are different from the Theory of Caring. The Theory of Caring focuses on the affective behavior and motivation of the nurse themselves.[114] Comfort Theory focuses on the patient and the act of responding to the needs of the patient from a holistic perspective.[115] In Comfort Theory, the patient is described as the protagonist of his or her care, being the leading and central role in the delivery and acceptance of care.[115]

Comfort Theory relies on holistic domains to assess the spectrum of comfort needs of an individual.[99] These four holistic domains include context related to physical, psycho-spiritual, environmental, and sociocultural needs of the patient. Physical needs have been described as being of the domain related to homeostatic conditions of physiology, sensation, and immune function.[99] Psychospiritual needs include those

related to psychological, self-esteem, self-awareness, sexuality, and one's own relationship with their divine being.[99] Environmental needs include concepts related to external comfort needs of the individual. Sociocultural needs relate to interactions with others including relationships with family and friends and the construct of culture.[99] Within these domains, there are three primary types of comfort including relief (where a person's comfort needs have been met), tranquility (where a person achieves a state of calm), and transcendence (where a person can rise above his or her discomfort or pain).[99,112]

Defining Comfort

Comfort has many meanings. The Oxford Dictionary describes comfort as being "a state of physical ease, and freedom from pain or constraint", "the easing or alleviation of a person's feelings of grief or distress", "a warm quilt" or as to "ease the grief or distress".[116] Kolcaba et al[117] describes comfort as having four separate definitions: (1) To have relief from discomfort; (2) to be in a state of ease and to have peaceful contentment; (3) to have relief from being in a state of discomfort; and (4) anything that makes things pleasurable or easier.[117] Another definition that has evolved from the Latin derivative of comfort is to strengthen, bring encouragement and support.[117]

Within these definitions, the interpretation of the word comfort can alter the outcome of trying to achieve comfort in an individual's care. Comfort can be a state of being. For example, when a person arrives home and feels the comfort of being in his or her own secure environment.[117] Comfort can also be given to another or to one's self through an act by providing a comforting measure, either physically or psychologically.

Comfort can be a construct in which the opposite of comfort is relieved or diminished. Comfort can also be provided by an object, such as a quilt or blanket.[117]

The individual's interpretation of comfort can be a complex construct. What may be known to bring comfort to one person, may not bring comfort to another. The idea of "what is comfort?" is very personal. An individual may only accept part of the definition of comfort when he or she internalizes its meaning. In addition, an individual may experience and interpret different levels of comfort based on his or her own preferences. These factors can influence the overall meaning of comfort and how it is defined by the individual.

Recent Uses of Comfort Theory in the Literature

In a qualitative, experience-based research design study, nurse researchers looked at the use of a care-research approach utilizing Comfort Theory.[99] Within a hospital setting of women patients who had sustained an acute myocardial infarction, the researchers utilized a systematic approach to evaluating individual patients' comfort needs within the physical, psycho-spiritual, sociocultural, and environmental domains. Following this evaluation, the nurse researcher described factors he or she had control over to influence the comfort of the patient. The study found that utilizing the Comfort Theory model allowed for the nurse and patient to build a rapport that centered around the context of care.[99]

The Theory of Comfort is also a model that supports a safe healthcare environment for patients. By establishing the concepts related to the Theory of Comfort, a recent 2016 paper describes how providers can create an environment that reduces

patients worries and fears by focusing on the aspects related to the individual patient's needs. In this studys' implementation of Comfort Theory, the health provider supports an environment of comfort through the absence of discomfort associated with the factors of worry and fear, and by reflexively supporting the patient's comfort.[115]

Comfort Theory Beyond Nursing Care

While the beginnings of Comfort Theory are grounded in the field of nursing, the approach extends beyond nursing care. It encompasses a compassionate approach to engaging with the sociocultural relationships of the human experience in health care. Similar to how nurse professionals play a proximal and uninterrupted role in the care of their patients,[115] other professionals, including physical therapists, also play a consistent, proximal, and uninterrupted role in the lives of their patients. Physical therapists are responsible for carrying out a plan of care, and providing care in a variety of settings.[118] In nursing education, student nurses are taught not only to perform an assessment that includes observing more concrete physical signs and symptoms, but to use their intuition, insights, perceptions, and past experiences to be able to more fully and holistically assess the patient.[114] Comforting requires the healthcare provider to have empathy and to be able to recognize signs of distress.[114] This further requires that the health care provider has an ability to notice verbal expressions of distress, as well as to read nonverbal cues, and physiological signs and symptoms. Physical therapists engage in critical reflection during patient care to look for signs of distress by utilizing cues from the patient to create a hypothesis and to look for pattern recognition based on previous experiences.[119] Given these similarities in the provision of care, it stands to reason that Comfort Theory would

be applicable to other professionals, including physical therapists, however, no other application of this theory is found in the literature.

Comfort and Caring in Physical Therapy Practice

Comfort is an important element of clinical care. The construct of comfort beyond the realm of nursing practice is a highly underrepresented yet a significant topic for healthcare professionals from all disciplines who provide therapeutic strategies in an attempt to meet the holistic needs of a patient. During the 2014 American Physical Therapy Associations' NEXT conference, Drs. Elizabeth Regan and Mary Swiggum recognized that physical therapist professional education does not sufficiently address personal factors that influence distress and discomfort.[120] As a partner in the healthcare delivery model, physical therapists are called to both identify and "maximize quality of life and movement potential"[121] in the areas of physical, psychological, emotional, and social well-being. [121]

Within the Guide to Physical Therapist Practice [122], the Physical Therapist Patient/Client Management Model describes how the care of a patient is managed throughout the provision of physical therapy services.[122] This includes the process of encountering the patient through an episode of care (examination, evaluation, diagnosis, prognosis, intervention and outcomes).[122] Within the Physical Therapist Patient/Client Management Model, there are many opportunities to deliver holistic care. Physical therapy in the United States is a profession that specializes in movement-related care. The vision statement of the American Physical Therapy Association that was adopted by the House of Delegates in 2013 is "Transforming society by optimizing movement to

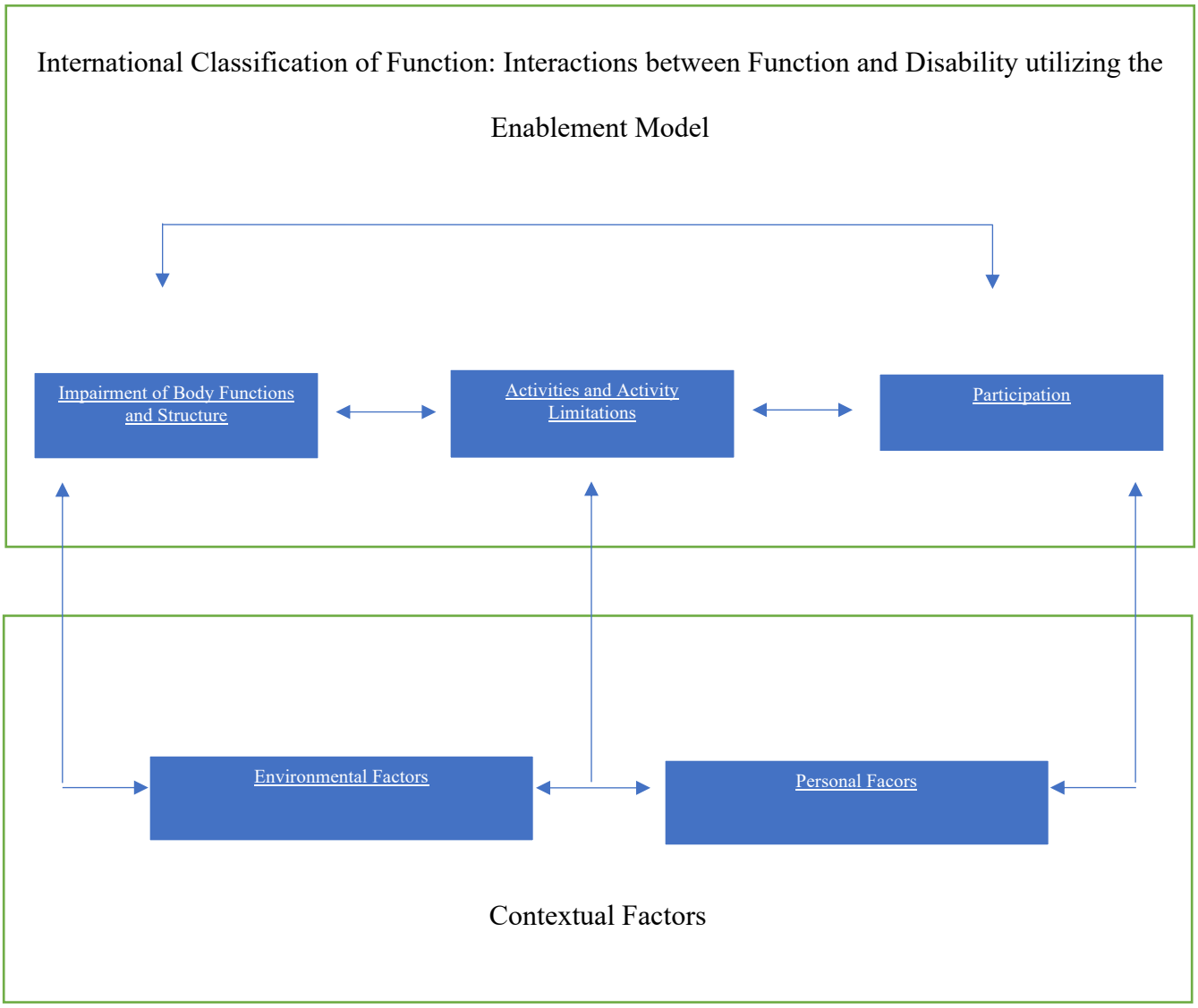
improve the human experience".[83] In the context of movement, we now understand that movement is not based around a closed system, but rather movement is a part of an incorporated system of perception,[123,124] cognition,[125,126] and bodily function.[127]

Optimizing movement as a physical therapist is based on the needs of the patient/client. Each patient is evaluated based on the context of the limitations presented by the disabling condition of the patient/client. Physical therapists are guided by the World Health Organizations (WHO)'s International Classification of Function, Disability, and Health, often referred to as the ICF Model.[30] The ICF Model organizes and classifies the impact of a health condition on an individual.[30] The concept of disability and function are used in the ICF Model to highlight both the strengths and limitations associated with an individual's level of functioning.[30] The ICF Model describes the interactions that occur with an individual's health conditions, its impact on the individual's body functions and structures, activities that they perform, and the levels of participation that the individual has in life-enhancing roles and responsibilities.[30] (See Figure 2.1: ICF Model) In addition, the ICF Model includes contextual factors that influence disability and function, including environmental factors and personal factors.[30]

Figures

Figure 2.1: ICF Model

Adapted from: How to use the ICF: A Practical Manual for using the International Classification of Functioning, Disability and Health (ICF). In. Geneva: WHO2013.



The physical therapist uses the ICF Model as a framework to better understand how an individual's health condition can impact his or her ability to participate in activities, roles, and responsibilities that are important to the individual client/patient. It is with the guidance of the ICF Model that the physical therapist looks beyond the impairments of the bodily structures, and understands those factors that bring quality to life for the individual. It is also with the guidance of the ICF Model that a physical therapist develops a plan of care that focuses on those factors that will be most beneficial to the client/patient's quality of life.

Contribution of this Study

This study will broaden the current understanding of the lived experience of parents who care for children with GMFCS Level V cerebral palsy. By understanding the lived experience of these parents, healthcare providers will be able to provide more comprehensive family-centered care and education. Having an overall better understanding of how parents experience and manage care for their child's pain and non-pain related emotional distress will help determine the interventions physical therapists employ with these children. This research will guide future research to advance physical therapy practice in family-centered care for children with GMFCS Level V cerebral palsy.

Summary

Children with severe forms of cerebral palsy may experience pain. However, as a condition of the human experience, they also experience other forms of distress.

Sometimes this distress may be associated with pain, and other times this distress may not be associated with pain. Because children with severe cerebral palsy often have limited communication skills, it is often difficult to determine what factors may be the underlying cause of their distress. Health care providers often utilize parent caregivers as a proxy for understanding their child's pain and emotional distresses.

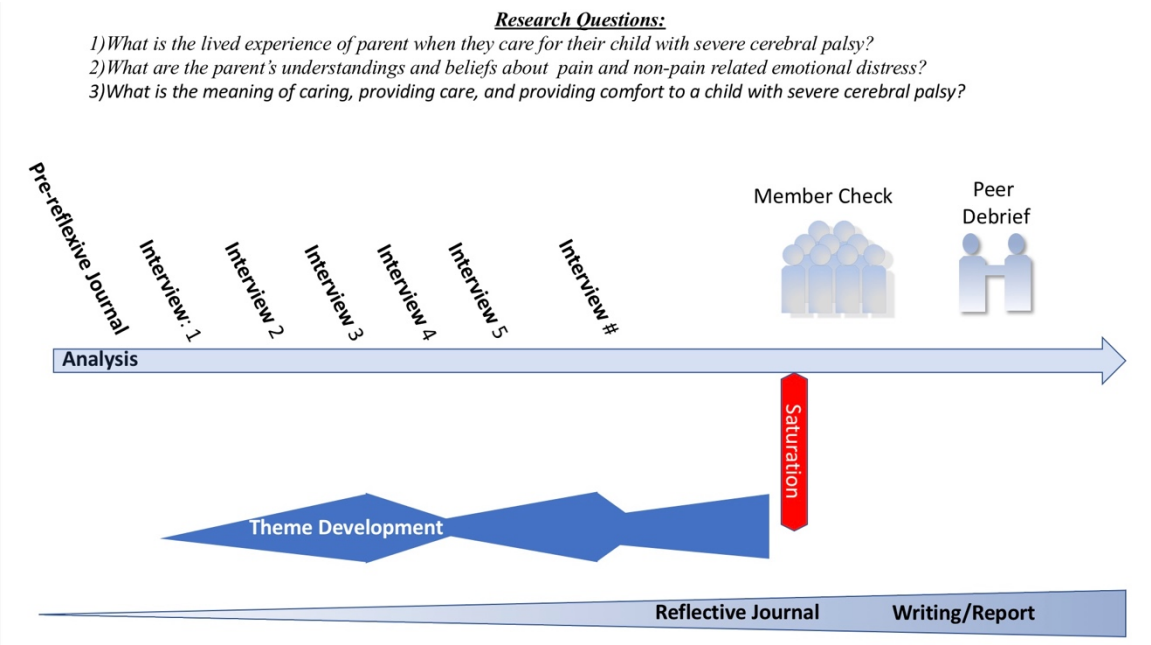
Living a life without pain or emotional distress does not automatically lead to a life of comfort. This implies that to improve an individual's quality of life, we need to consider pain, non-pain related emotional distress, and comfort. There are different theories that explore care and comfort in health care. Parents and physical therapists play key roles in understanding pain, non-pain related emotional distress, and comfort in children with severe cerebral palsy. Additonal research is needed to understand pain, non-pain related emotional distress, and comfort in children with severe cerebral palsy.

Chapter 3: Methods

Introduction

This chapter includes the research methodology and research methods of this study. It will review the research questions and provide a background of hermeneutics phenomenology. This chapter describes the participant parameters, recruitment strategies, and the method for data collection. Lastly, this chapter describes the modes of analysis that were carried out by the investigator. A schematic overview of the study structure is provided. (see Figure 3.1: Schematic Overview)

Figure 3.1: Schematic Overview



This schematic describes the iterative process that will occur for each research question of this phenomenological study. The highlights of the schematic shows: 1) Analysis is ongoing through the entire process. 2) As the interviews proceed, theme development changes and evolves. 3) Once themes stabilize, saturation is reached. Member checking and peer debriefing will occur. 4) Writing is an ongoing process of reflection, discovery, and reporting.

The purpose of this study was two-fold: (1) to understand and describe the experience of parents who care for children with GMFCS Level V cerebral palsy, and (2) to understand these parents' perceptions and beliefs about managing pain and non-pain related emotional distress. The research questions that guided this study were as follows:

1) What is the lived experience of parents when they care for their child with severe cerebral palsy?
2) What are the parent's understandings and beliefs about pain and non-pain related emotional distress?
3) What is the meaning of caring, providing care, and providing comfort to a child with severe cerebral palsy?

Research regarding pain has been investigated in children with severe forms of cerebral palsy, however, there are not any published studies that examine parental beliefs or perceptions of pain and non-pain related emotional distress.

This study utilized a qualitative research approach to answer the research questions. Qualitative research comes from a rich history of philosophical evolution that brings insight to the world in which we live.[128] As discovery of knowledge through positivistic natural science methods does not sufficiently provide meaning to the lifeworld, the philosophical evolution of post-positivism supports scientific inquiry into human-based experiences.[129] Within the post-positivism and constructivism paradigm, qualitative researchers perform methods that are not completely pre-determined, but that are enacted based upon the research question and contextual circumstances that unfold as the study is being conducted.[128,130] Qualitative studies often focus on the narrative in

which relationships of information are compared in order to derive patterns in the narrative, often creating themes and categories for understanding the collected data.[131] Therefore, a qualitative methodology was the most suitable method for looking into the topic of understanding parental lived experiences and the understanding they have of their child's pain and emotional distress, to answer research questions pertaining to parental perceptions and beliefs, and to investigate the meaning of caring, and providing care and comfort.

Phenomenology

Phenomenology is a qualitative research approach aimed at exploring the lived experience associated with the daily occurrences of human beings.[132] Within phenomenology, there are two main approaches; descriptive (eidetic) phenomenology and interpretive (hermeneutic) phenomenology.[133] Edmund Husserl (1859-1938) is often associated with the beginnings of phenomenology, and set the path for the rise of the descriptive approach.[133,134] At the time, he criticized researchers in psychology because of their attempt to apply rules associated with quantitative methods to experiences that are not based on automaticity and reflexes, but rather individual human perceptions and experiences.[134] He believed that human experiences can be studied and that these subjective experiences are an important part of the scientific inquiry because human action and motivation are influenced by humans' perceptions of what they believe are real.[133] In his work, Husserl explored the concept of consciousness.[134,135] Exploring the idea of intentionality, he concluded that the mind is directed towards objects for building reality.[134,135] By understanding this reality, one can understand the "essence" of an

experience, or the true meaning of a phenomenon.[134,135] Within descriptive phenomenology, the essence or the structure of consciousness surrounding the phenomenon can be captured through phenomenological reduction, also known as bracketing.[104,134,135] Bracketing is a process in which all preconceived ideas and experiences are removed from the interpretation of the object of study.[135] Husserl believed that removal of context and history would allow for the exploration of the true essence of the phenomena, allowing for the universal experiences to be captured.[133]

The interpretive (hermeneutics) approach to phenomenology was realized in part by an apprentice of Husserl, Martin Heidegger, who believed different assumptions were necessary to be able to capture the understanding of lived experiences.[133] Heidegger believed that Husserl's method of studying human experience through epistemology was misguided, and that an ontological view of "being" provides a deeper and richer understanding of the human experiences.[136] Heidegger, along with another philosopher, Hans-Georg Gadamer, both referred to the importance of historicality, where the individual's experiences are influenced by social and cultural contexts.[135,137] Husserl believed that these contexts needed to be bracketed by the researcher in order to describe the lived experience of a phenomenon.[104,134,135] Heidegger, however, believed that these experiences were an essential component of understanding lived experiences under study, and included the awareness brought to the topic by the researcher.[136,138] Within his interpretive, hermeneutic approach, rather than bracketing, the researcher acknowledges their experiences by reflecting on their own perceptions and beliefs about the phenomenon.[136,138] Moreover, Heidegger believed that when attempting to understand a phenomenon, it was important to understand how the parts influence the whole, as well as

how the whole influences the parts.[134,136] This is what is referred to as the "hermeneutics circle".[134,136] Within the context of interpretive phenomenology, the hermeneutics circle is used to gain understanding of the lived experiences of the individual, the investigator, and the phenomenon in its entirety, and therefore the process of interpretive phenomenology is iterative.[138]

This study utilized the interpretive (hermeneutics) approach of phenomenology. Within interpretive phenomenology, Max Van Manen provides a supporting organizational structure for reflexivity and analyzing data.[132] Reflection is a fundamental key to understanding a phenomenon utilizing this approach. Van Manen identifies what is referred to as the four fundamental existentials, that when combined, assist the researcher in identifying the lifeworld, or lived world, of the participant.[132] These four existentials; lived space (spatiality), lived time (temporality), lived body (corporeality), and lived other (relationality, communality) are key components to understanding a rich and meaningful description of the studied phenomenon.[132, 139] Lived space, or spatiality, refers to the feeling of spatial surroundings, rather than an actual dimensional space surrounding an individual. Lived time, or temporality, is the sensation of time. The lived time of a phenomenon often creates a perception of time passed. Lived body, or corporeality, is the experience within the human body or of the human body surrounding the phenomenon being investigated. Lived other, also referred to as relationality or communality, is the perceptions of our relations to others and feelings of connectedness within a phenomenon being investigated.[132] Through a reflective process, themes of a phenomenon are exposed and essential qualities are identified, that without those qualities, would not identify the essences associated with the phenomenon.[132] Van

Manen's ideas of lived space, lived time, lived body, and lived other was utilized to assist in structuring the process of interviewing and analyzing data obtained in this study.

Participant Information

Participants included parents who care for their children with GMFCS Level V cerebral palsy. Children were not included as a participant in this study. Inclusion criteria included being a parent of a child with GMFCS Level V cerebral palsy between the ages of 4 and 17 (See Table 3.1: Inclusion/Exclusion Criteria). The age of 4 was the minimum age for the participant's child due to the diagnosis of severe cerebral palsy with a GMFCS Level V being not fully established until the age of 2.7 (2.0 - 3.7 95% CI), where the upper end of the 95 percent confidence interval is equal to just under 4 years of age according to Rosenbaum et al.[60] Parents had to be biological or adoptive in nature. When including a parent, they were required to participate in some primary role in caregiving for their child. The participant's child needed to reside at the home with the caregiving parent. In the case of a child who has a split residence, the caregiver needed to be able to self-identify as a primary caregiver.

Table 3.1: Inclusion / Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
• Parent of child with GMFCS Level V cerebral palsy between ages of 4 to 17 years • Acts in a primary caregiving role for the child with severe cerebral palsy	• Parent does not view him or herself as a primary caregiver • Non-english speaking

Participant Recruitment

A purposive sampling method was used for this study. Participants were recruited in 3 recruitment sites including Iowa, Michigan, and Florida to obtain a sample with a larger geographic representation beyond the immediate region of the primary investigator. Participants were recruited using a flyer that was distributed by physical therapists who have worked with children with cerebral palsy GMFCS Level V. (see Appendix A: Participant Flyer) Therapists were educated by the primary investigator via e-mail, telephone, and in person as to the nature of the study so that they could assist in recruiting participants. These therapists provided their patients' families information about the study via the flyer. If the parent wished to participate, they were asked to contact the primary investigator. Once the parent contacted the primary investigator, additional information about the study was provided and the primary investigator determined the parent's willingness to participate in the study.

Informed Consent

Approval was obtained from the Institutional Review Board (IRB) at Des Moines University. Additional approval was obtained from Nova Southeastern University. An IRB Authorization Agreement was formed between Des Moines University and Nova Southeastern University with oversite IRB at Des Moines University. Once a potential participant contacted the primary investigator, a discussion took place with the participant regarding the inclusion criteria for participation. Questions regarding the participant's child were asked to determine if the child functioned at a GMFCS Level V. The primary investigator reviewed the GMFCS Scale[5] and the diagnosis with the parent to assist with

this endeavor. Once the parent agreed to participate, the primary investigator obtained informed consent from the participant. (see Appendix B: Participant Informed Consent). The child was not a participant in the interview process.

Data Collection Method

The primary data sources for this study were the parent cargivers and the primary investigator. The method of data collection was in the form of qualitative interviews with the parent caregivers, dictated and written journal entries performed by the parent caregivers, and field notes taken by the investigator during the interview process.

Interviews: Operational Definitions

The following protocol refers to both the pilot and the participant protocol and both parties will be referred to as "participant" in this section.

Prior to the interview day, the participants were provided with the purpose of the study and were asked to voice record or write about any thoughts that they had prior to the interview day regarding the study topic.

Once the participants were recruited and informed consent was obtained, the primary investigator and the participant met at a location in which the participant agreed upon. This location was a private location. These locations included office space and rooms that provided a space for a private discussion and at the homes of the participants. The goal of this space was to provide an environment where the participant felt relaxed and safe to be interviewed about the study topic. The participants were asked verbally for

permission to begin recording. Once the recording began, the interview process proceeded. None of the participants requested to stop the interview or leave the study.

Data Collection Method: Interviews

Interviews are the most common method for obtaining data in phenomenological qualitative research.[140] The interview provides a venue for obtaining rich and descriptive information pertaining to the individual's lived experience.[141] Through the dialogue that takes place in the interview process, the participant opens a gateway into the perceptions of his or her lifeworld.[142]

There are different types of interviews that can be used in qualitative research including unstructured, semi-structured, and structured interviews.[143] Researchers use the unstructured interview in field studies where the researchers' goal is to understand the participants experiences without much context or knowledge of the topic.[141, 143] The unstructured interview has no guidance questions and is comprised of informal conversation about the participants experiences.[141,143] The semi-structured interview, also referred to as the general interview guided approach, uses an interview schedule allowing for a framework of discussion within the interview.[143] Within semi-structured interviewing, the questions are posed in an open-ended format in which spontaneous discussion can take place to allow for the researcher to dig deeper, and gather a rich description.[143] Lastly, the structured interview consists of a set of planned questions that do not allow for any deviation from the questions posed.[143]

The interviews in this study were of a semi-structured format, and were conducted individually with each participant. The interview was informal and conversational to

allow for a fluid dialogue that was based around the phenomenon under study. In this way, the interview maintained a focus around the theme of the research topic, while also allowing for an open conversation that provided a window of opportunity to view the contextual lived experience of the participant.[142] Guidance questions were created to produce open-ended responses based upon the lived experience as told by the participant. An interview guide provided guidance questions to assist the researcher to focus on the research topic. (See Appendix E: Interview Guide) Guidance questions consisted of open ended words of who, what, when, where, how, and why[144] and avoided the use of leading questions.[142] Questions were used within the semi-structured interview. The interview was also guided by the theme and the participants self-described experience around that theme. The focus of these guidance questions were based on the primary research questions of this study:

1) What is the lived experience of parents when they care for their child with severe cerebral palsy?
2) What are the parent's understandings and beliefs about pain and non-pain related emotional distress?
3) What is the meaning of caring, providing care, and providing comfort to a child with severe cerebral palsy?

During the interview process, following each of the guiding questions, the researcher provided additional follow up questions that were created in the moment to help discover in-depth details pertinent to the participants' lived experience of the phenomena.[144] The goal of the primary investigator was to provide follow-up questions that uncovered or

revealed rich, deep insights into the participant's lived experience as a parent of a child with severe cerebral palsy.

Data Collection Method: Self-Initiated Voice Recorded or Written Journal Entries

Prior to the interview session, the participants were asked to self-initiate voice recorded or written journal entries on the subject matter of pain, emotional distress, and the well-being of their child. Journal entries by participants are a rich source of data.[145,146] Benefits of using journal entries as a source of data includes efficiency, the ability to allow the participant's responses to be at a self-guided flow, and the ability for the participants to speak on what they feel is important.[146] In this study, the participants were instructed to voice record or write as many times as they would like over a two week period, from one entry to unlimited entries. If the participants chose to voice record, they were provided a voice recorder for this task. This style of data collection was open-ended and unstructured. The participants were instructed to secure this voice recorder or written journal for personal privacy and included instruction to keep the voice recorder only on their person, or leave it at their home so they did not lose the voice recorder. The primary investigator collected these voice recording or written journal entries to gain an understanding of the participants' innermost and uncoerced thoughts of the study topic. In this way, this data was able to assist in preparing the participant for the interview and provided additional data for triangulation of catetgories and themes during the analysis, verification, and reporting of the study findings.

Data Safety and Protection

Raw data was collected using two different digital recording devices, in the event one recorder did not work, and through written field notes. Digital data was stored on both an encrypted drive and on an encrypted computer. During travel, the recordings were transferred to the encrypted laptop and erased from any voice recorder prior to travel to secure the data. The drive and computer were stored in locked environments [university office, home, vehicle] accessible only to the primary investigator via a key. Each participant was identified on a participant identification form with a participant pseudonym at the time of recruitment. The Participant Identification Key (see Appendix F: Participant Identification Key Form) was maintained within a locked drawer, within the locked university office of the primary investigator. The Participant Identification Key was destroyed for complete de-identification once the data was analyzed and thematic categories were established.

During the transcription phase, the participants' names were replaced with each participants' pseudonym. During the transcription phase, other individuals identified during the interview process (i.e., son, daughter, husband, ex-husband, grandfather) were identified with pseudonyms as well.

The investigator took notes during the interview process. Participant pseudonyms were used. As an extra precaution to ensure participant confidentiality, following the interview, the notes were reviewed and any identifying names or information that was mistakenly recorded was removed. The notes were scanned into digital form for later

review. The paper notes were destroyed. After seven years from the completion of the study, all raw data will be destroyed.

Validation Methods

Establishing Trusworthiness

It is important to establish scientific rigor that promotes a high quality study grounded in sound scientific methodology. Validation of qualitative research is established through procedures of trustworthiness and authenticity.[130] Trustworthiness is safeguarded through the procedures of validity found in qualitative research.[130] Authenticity is the faithful representation of the findings in conveying or relating the experiences of the participant or of the phenomena.[147,148] Criteria guide the investigator in a rigorous process to give value to the study's process and findings.[147-150] Lincoln and Guba,[149] pioneers in establishing such criteria, presented four primary criteria to establish trustworthiness in qualitative research: credibility, dependability, confirmability, and transferability.[149] Whittemore and collegues referred to this as finding the "truth value of multiple perspectives."[147] Since the introduction of these four criteria, additional criteria have been discussed in the literature,[147] however these four criteria continue to exemplify trustworthiness in qualitative research.[148,151-153]

Criteria: Credibility, Dependability, Confirmability, and Transferability

In qualitative research, credibility is established when the data and interpretation is reflective of the participants' experiences.[148] Qualitative researchers use techniques to verify that participants would recognize the data and its interpretation as a part of their

own experience.[148] Credibility can also refer to the aligment of the data analysis and the intended focus and findings of the study.[154] Techniques include prolonged engagement with the participant and audit trails to capture ideas, processes, and changes over time.[148]

Dependability of a qualitative study refers to the agreement of the data and intepretations across all of the participants.[148] It is often compared to the criteria of reliability in quantitative studies.[147,155] Techniques to establish dependability in the data include member checks wherein the researcher follows up with participants following the data collection, and peer checking or debriefing in which a collegue or expert reviews some of the data to ensure that the researcher has correctly analyzed and interpreted the data.[155]

Confirmability refers to the extent that there is some concept of neutrality on the part of the investigator and that the interpretation of the data is based around the participants' experiences and does not include investigator bias.[131,149] Techniques to help establish confirmability include audit trails, engagement with the participants, member checking, peer checking, reflexive journaling acknowledging the investigators perspective, and use of exemplars in the presentation of the data.[147,148]

Transferability refers to the ability of the findings to reflect other settings or groups and is similar to external validity in quantitative studies.[154] In this way, transferability is the readers ability to transfer the knowledge from the findings to other circumstances or contexts.[154,155] Examples of techniques that ensure transferability include peer checking and providing rich, thick descriptions.[149,155]

These criteria were utilized throughout the methods to ensure that this study followed rigorous practices in order to establish trustworthiness. Table 3.2 provides the criteria and the techniques that were incorporated into this study (see Table 3.2: Trustworthiness Criteria).

Table 3.2: Trustworthiness Strategies Utilized in this Study

Trustworthiness Criteria	Strategies Being Used in Study

Credibility	• Prolonged engagement with participants
	  ○ Self-initiated recording
	  ○ Interview
	  ○ Member Checking
	• Audit trail of process, descisions, and ideas

Dependability	• Member check with participants
	  ○ Participants review transcripts
	  ○ Some participants review findings
	• Expert review of data and data analysis process

Confirmability	• Audit trail of processes, decisions, and ideas • Participant engagement • Member checking of transcripts • Researcher peer checking • Reflexive journaling • Use of exemplars
Transferability	• Researcher peer checking • Providing thick description

Reflexive Journaling

To establish confirmability within this study, the process of reflexive journaling was employed. The primary investigator engaged in reflexive journaling to establish his own perceptions, biases, feelings, and knowledge of the subject area throughout the process of data collection and data analysis.[156] In hermeneutic phenomenology, writing is a continuous part of the journey towards understanding and not simply an end stage activity to summarize the findings.[132] This process of reflexive writing helps establish the enlightenment that occurs with the process of understanding one's own ideas related to the topic.[134] By performing reflexive journaling, ideas can be explored to gain insight to the participant's experiences and the interpretation of the meaning of their ideas.[134] This process of reflexive journaling allowed the primary investigator to orient to the phenomena as he engaged with each participant.[156] Throughout the process of data collection, the primary investigator continued to engage in reflexive journaling, contemplating his beliefs about the topic area. As the data were continually analyzed, the investigator continued to document his thought experiences of the topic and its participants. In hermeneutic phenomenology, as the data are analyzed, the reflexive journal becomes a part of the audit trail.[151] The process of reflexive journaling enhances the trustworthiness of the study by providing credibility and dependability to the study.[147] By being transparent with ideas and reflective thoughts, the researcher is actively engaged with the topic of study.[156] In addition, reflexivity allows the researcher to become aware of his own biases and to gain an awareness of his infleunces on the interpretation of the data.[156] Max van Manen[132] writes about the importance of the researcher to orient themself to the phenomena.[132] van Manen believes that writing is

essential to the process of orientation and interpretation of the data. The textual representation of the researchers thoughts, combined with the textual interviews produce emerging themes.[132] The following is a pre-study reflection from the primary investigator:

I realize my history provides me with a unique perspective on the topic of caring for the population of individuals with GMFCS Level V cerebral palsy. When I was 18 years old, I started my first "caregiving" job as a resident assistant for a care facility for children with special needs. I befriended a resident who was the same age as me, and we still remain as close friends today, almost 22 years later. While severely physically impaired and unable to physically control his movements, he was uniquely attentive and communicative in his own way. I quickly realized that there was a lot that he was trying to communicate, although he could not express it. It was apparent that he took to my interest in communicating with him. I was his favorite caregiver. It is funny to consider this now, as he moved out of that care facility into an adult care facility less than a year after I started working there. We established a communication system where he would look towards his left for "yes", and his right for "no". As I began to understand his interests, I was able to ask him questions. I learned details about his interests and quickly became his best friend, and he became mine. He moved to an adult care facility and we maintained our friendship. I knew that he missed living with his parents, even though he moved to a care facility when he was 11. I knew that he had a sense of humor, and I knew that he loved his father more than anything in the world. His family was involved, and his parents appreciated our friendship. His parents would say that I opened a world to him by becoming his friend.

I knew what it took for me to understand his world. It required me to understand his interests, his life story. Having been a caregiver and also moving my way through school to become a physical therapist, I also knew what caused him discomfort and physical pain. He has spastic athetoid cerebral palsy and would be classified on the GMFCS as a Level V. He eats orally, however, it is difficult. There are times when he would cry, and it was because he missed his father. They had an extremely strong bond. There were times when he grimaced and even cried, and it was because his legs were spasming. I remember one of the first times we noticed this. He, his father and I were walking through a grocery store. He got upset, with tears in his eyes. I asked him what was wrong, and he looked down. His father was not sure what was happening. At first we asked if it was something he was thinking. His response was vague, and not definitive. His facial expression did not seem to respond one way or the other to my question. This vague response was not like him. I knew his emotional cues. Often to express his emotions he would extend in his chair, his head lifting above his headrest. During times of expressing emotional stress, he was not guarded with his body, but was expressive. We initially started asking him questions about his father, his parents' home- all to no avail. In this moment and in these discussions, he was guarded with the movement of his body. I asked him if it was his legs. He turned his head to say yes. I asked if they hurt. He turned his head to say yes. I then unstrapped his feet from their foot straps and began to gently move his legs, and he calmed. It was in this moment that I realized that it was important to be able to distinguish emotional distress and pain in my friend. He was expressive with his emotions. It was easy to identify them in him because he is such an interactive person. However, in this moment it was insightful to realize how much pain he

could experience because of his condition, and how necessary it was to be able to understand these cues that differentiated emotional distress from pain. It was more common to turn to psychosocial questioning because of his typical conversational interactions, however, something wasn't right- which began the questioning surrounding pain.

This is one example of how understanding the whole of an individual with GMFCS Level V cerebral palsy can help influence decisions on what type of care needs to occur. While my friend's ability to communicate was at an advanced level for somebody with GMFCS Level V cerebral palsy, this interaction allowed me an opportunity to become engaged with the sensitivity needed to care for individuals with this level of cerebral palsy. H*aving been a pediatric physical therapist for 14 years, I have empowered parents of children with this type of cerebral palsy to know and understand their child's world experience to help them decipher their child's unique communication. I have seen children begin their therapy with concerns of physical pain, where the child is closed into a world that avoids external stimulation. I have seen some of these children blossom to an awareness of initiating communicative interactions through facial expressions, head turns, and movements that allow the parents to decipher cries associated with physical pain, and groans associated with emotional distress.*

My experience in working with parents who care for children with GMFCS Level V cerebral palsy has been vast over my 14 years of pediatric physical therapy. I find that parents want to partner with others who care, both in the sense of providing care, but also in the sense of concern that is had for the well-being of their child. They don't want

to be judged for wanting the most for their child, and I also perceive that they don't want their child to be judged based solely on the outward appearances of their condition.

As a physical therapist, I have had to tap into the psychosocial experiences of my patients through holistic care in order to collaborate with families to help their child reach their greatest point of well-being through optimal function and state of being. I believe that there is a way to approach families of children with this type of cerebral palsy to help empower families to know and understand their child so that they can better advocate for their child. However, I know that my experiences are my own. I know that many others also have experiences. I want to be able to have a better understanding of their lived experience.

As I begin to recruit participant and explore their lived experiences I anticipate that including a wider spectrum of child age ranges of 4 to 17 may introduce some covariates into the discussion of pain and non-pain related emotional distress. I anticipate that parents and their children will experience different types of stressors throughout the life of their child. I believe that narrowing this age span may impact recruitment possibilities due to the participant limitation. In addition, these stressors may be inconsistent from child to child, and parent to parent, regardless of the age of the child. However, I may find that while parents experiences are different, the underlying causes of their experiences may have common themes.

When it comes to the discussion of pain and emotional distress, I believe that at times parents struggle with deciphering pain from emotional distress. When approached about the question, I anticipate that some parents may look to environmental factors,

social factors, timing of occurrence, child's fatigue level, child's position combined with child's movement, and interventions to relieve distressing behaviors as factors that influence their understanding of their child's pain and emotional distress. However, another characteristic that I anticipate parents may feel include doubt surrounding "getting it right". I do believe that this may be where the parents lean on the physical therapist to help them explore the different causes of their child's distressing behaviors, whether due to pain or emotional distress. Throughout this study, I will be collecting data pertaining to these ideas and concepts. I will continue to journal about my thoughts pertaining to the study so that it can become a part of the recorded data.

Mentorship

In phenomenological qualitative research, the interview becomes the measurement tool. To establish a valid interview tool for this study, the primary investigator completed a mentor-apprenticeship process to hone his interview skills and qualitative analysis skills. This process has been described as being the most favorable method for learning qualitative interviewing and analysis.[142] Within this apprenticeship process, there are not any established rules; however, the novice investigator learns through communities of practice, engages in discussion with peers and experts, listens to qualitative interview recordings, and gains hands-on experiences.[142,157] The investigator of this study was engaged in a dissertation process in which guidance came from the expert dissertation chair. In addition, the researcher worked in a community of quantitative and qualitative researchers. He held a round table discussion on March 10, 2017 to engage his local research community in a discussion about this study topic area, the moral implications, and the methods for establishing trustworthiness in its findings.

The primary researcher continued to engage in his community of researchers following this event. The primary investigator practiced qualitative interviewing to prepare him for this study. In addition, the researcher engaged in pilot interviews.

Pilot Interviewing

A pilot interviewing process was used to refine the processes of data collection in this study. [142,157] The pilot interviewing process prepares the interviewer to become the research instrument in a qualitative interview based study.[142] The interview questions asked in qualitative interviews are open ended to allow for discovery of the participants' lived experiences.[144] (see Data Collection Methods above). As such, the pilot interview process is necessary to establish rigor in instrumentation in the research process.[144] In the pilot interview process, the researcher participates in smaller versions of the proposed study.[142] This allows for the researcher to administer the interview in the same manner that will be performed in the primary study.[144] Ronald Chenail (2011) provides a list of benefits to performing the pilot interview (see table 3.3:Chenail's List of Benefits for Pilot Interviewing).[144] Pilot interviewing can be performed on participants not included in the study to prepare the study for data collection.[141] Pilot interviewing with non-participants of the study can help build confidence in the researcher, assist in determining if there are weaknesses in the design of the study, and can help evaluate the interview guiding questions for use in the study.[141] The pilot data was not intended to be a part of the study, however, information obtained from the pilot interview did help provide direction for the guidance questions in the interview process. The pilot interview process helped establish credibility and dependability for this qualitative research study. (See Table 3.4: Purpose of the Pilot Inteview)

Table 3.3: Chenail's List of Benefits for Pilot Interviewing

Chenails List of Benefits for Pilot Interviewing [144]
1) The researcher can administer the instrument as it will be performed in the primary study
2) The researcher can ask questions to the participant to establish inquire about any problems with the questions
3) Determine the amount of time necessary to complete the interview process
4) To get rid of unnecessary questions
5) Assess each questions ability to provide open range responses
6) Determine if the replies to the questions are interpretable
7) Determine if all questions are answerable
8) Reword or rescale problem questions
9) Shorten, revise, or re-pilot

Table 3.4: Purpose of the Pilot Interview [144, 181]

Purpose of the Pilot Interview
1. Testing questions / guiding questions for suitability and feasibility
2. Forming the research protocol of the interview process including time needed to complete the interview process
3. Testing the recruitment method
4. Helping to solve logistical problems
5. Estimating data variability
6. Establishing necessary resources for the primary study
7. Further assessing how the data will be analyzed
8. Providing additional training for the researcher
9. Supporting the studies rigor for possible funding
10. Supporting the study as being credible to external stakeholders

144,181

Two separate pilot interviews were performed on 2 individuals. These pilot participants were parents of an adult child with GMFCS Level V cerebral palsy. Parents of an adult child were used in the pilot interviewing process to avoid utilizing potential research participants. In this process, the global questions were honed to establish the overarching interview questions /guiding questions for this process. The piloting participants were recruited utilizing the same mechanism as established in the participant recruitment section of this study (See Appendix C: Pilot Flyer). The pilot participants provided informed consent before the pilot interviews took place. (see Appendix D: Pilot Informed Consent)

Data Analysis

All data was digitized. Any notes taken were processed into Portable Document Format (PDF) documents. Digital recordings were transcribed to textual format. The transcription were performed by a professional transcription service. Transcribed documents were reviewed by the primary investigator for accuracy. Data was then uploaded to Qualitative Data Management Software (QDMS) NVivo (Version 12). The data was analyzed for categories through constant comparison. Throughout the process of constant comparison, as the data was collected, categories and data sorting was altered based on the various themes identified in the data. Data was saved as a log throughout the process following the addition of each new participant to create a progressive log of the changes in order to capture the decisions being made throughout the analysis process. This detailed log will help establish dependability of the data and its findings.

The analysis that was performed followed the method as described by Max van Manen.[132] Through this reflective process, the structures of meaning of the phenomena were explored, as lived by the collective group participant.[132] The process of creating themes, in the context of phenomenological inquiry, is to discover understanding and "seeing meaning" from the perspective of the participants.[132] Analysis of the data is not a predefined, linear procedure, but rather a process as described by Max van Manen, of "insightful invention, discovery or disclosure".[132] Through an act of constant comparison, Max van Manen describes a process of analyzing the part and the whole.[132] He further delineates three different processes that can formalize and take shape as the analysis takes place: wholistic, selective, and detailed methods. The wholistic or sententious approach is one in which the researcher takes an overarching look at the data to discover overarching themes. Using only with this approach could lead to error, as different observers may create different themes from this overarching viewpoint.[132] Within the selective or highlighting approach, the researcher reads and re-reads text, attempting to find meaning within the most essential or revealing phrases.[132] The detailed or line-by-line approach is one in which each separate sentence or cluster of sentences are analyzed for revealing qualities about the phenomena.[132] A combination of these methods allows for the researcher to look at the part and the whole. During this process of discovery, categories and themes are born. To better understand what a "theme" is, he defines the word theme, and describes qualities of themes. (see Table 3.5: Max Van Manen: Theme Defined) In the context of hermeneutic phenomenology, theme is a textual characterization of the phenomena as it is interpreted through reflective analysis.[132] This procedure of data analysis as layed out by Max Van Manen was performed. I collected the data through the

interview and journaling process previously defined. I listened to the recordings while reviewing the text, performing a line-by-line approach. Categories were established utilizing an iterative process. As new data was collected, data was reviewed and a combination of line-by-line approach and highlighting approach was used until the data and categories became saturated. Following this, each of the categories were further separated into the four existentials of corporeality, spatiality, relationality, and temporality. This was performed to engage with the textual data for further interpretation through a hermeneutic phenomenological process as I began to engage with the data through a wholistic approach. Themes were able to be established following this procedure to provide a rich description of the data.

Table 3.5: Max Van Manen: Theme Defined

From Researching Lived Experience by Max van Manen[132]
Themes are:
… "the experience of focus, of meaning, of point" [132] **… "at best a simplification" [132]** **… "not objects one encounters at certain points or moments in the text" [132]** **… "the form of capturing the phenomenon one tries to understand" [132]**
Themes have:
… " a desire to make sense" [132] **… "a sense we are able to make of something" [132]** **… "an openness to something" [132]** **… "a process of insightful invention, discovery, disclosure" [132]**

Member Checking

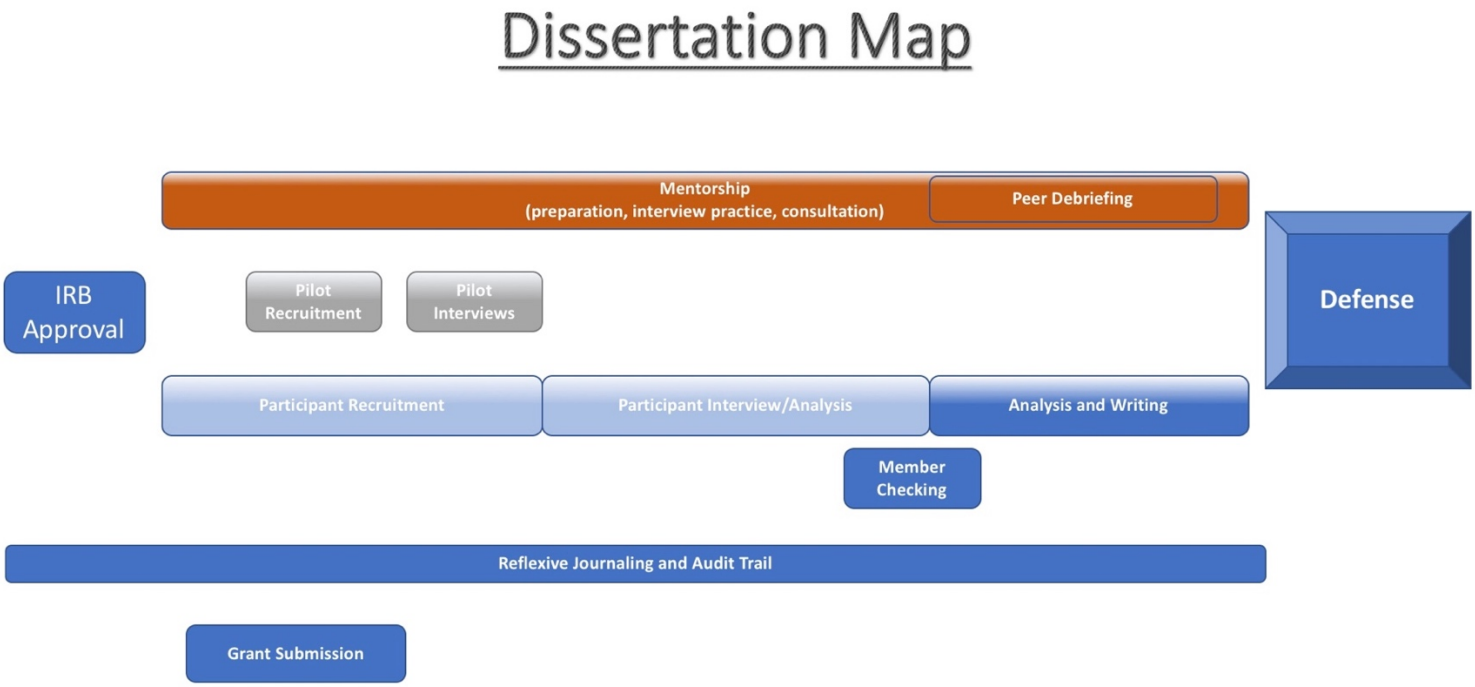
A total of four participants were selected as reviewers. These participants reviewed the discovered themes and categories for accuracy and their thoughts were shared with the primary investigator. In addition to member checking, a peer debriefing took place.

Peer Debriefing

The primary investigator participated in a peer debriefing. Peer debriefing is supported as a method to bring credibility to this study.[151] Peer debriefing reviews the researchers work, including background information, collection and data-management procedures, data, analysis procedures, and analysis and findings.[140,158] The peer debriefing was performed with the researchers collegues of pediatric physical therapists, a pediatric speech language pathologist, and academic collegues.[151,159] Overall, peer debriefing provided an opportunity for this study to be viewed and commented on by other members of the topic community, to build upon the quality of the findings, to evaluate the overall process, data, and themes to establish credibility of the work, and confirmability or neutrality and accuracy of the data.[152]

Figure 3.2 outlines the full dissertation process. (Figure 3.2: Dissertation Map)

Figure 3.2: Dissertation Map



Chapter 4: Findings

Introduction

There were eleven participants that were included in this study. Participants were recruited from three different states, Iowa, Florida, and Michigan. Demographic information can be viewed by looking at Table 4.1 (Participant Demographics). The participant age range was 35-53 years. To maintain participant anonymity, participants and the participants family members were given pseudonym names. A list of pseudonym names are provided for each participant in Table 4.2 (Participant Pseudonyms). Ages of children are defined in ranges to assist in maintaining anonymity of the participants. Saturation of the data was obtained. The data was analyzed utilizing a hermeneutics phenomenological process as described in Chapter 3: Methods.

Table 4.1 Participant Demographics

Number of Participants	11
Age Range of Participants	35 – 53 years
Age Range of Participant Children	4 – 16 years

Table 4.2: Participant Pseudonyms

Participant Name:	Child with Cerebral Palsy Name:	Childs Age Range:	Additional Names and Relationships:
Dan	NA	Old Child	NA
Hope	Alyssa	Adolescent	Kevin (husband) Chase (son)
Hannah	Bobby	Child	Jerry (husband) Polly (daughter)
Josh	Thomas	Child	Sandra (wife) Jon (son)
Julie	Jack	Adolescent	Bill (husband) Jake (twin-brother)
Kelly	Bradly	Young Child	
Kelsey	Jeffrey	Old Child	Greg (husband)
Kim	NA	Child	Britta (sister)
Mark	Brady	Teenager	Beth (wife)
Tricia	Michael	Teenager	Jim (husband) Natalie (daughter) Braden (son)
Zach	Emily	Adolescent	Jean (wife) Nick (son)
Ages Ranges: Young Child: 4-5 years; Child: 5-8 Years; Old Child: 9-10 years; Adolescent: 11-13 years; Teenager: 14-17 years. NA= Direct names were not used within the quotations of the findings.			

Themes

Theme 1: Life is Hard; Heavy with Burden, Worry, and Love

The life of a parent with a child with severe cerebral palsy is heavily burdened with duty and worry. Yet this strenuous responsibility is offset by unadulterated warmth, love, and affection. Every parent talked about how the weight of each day is always present and filled with duties that orient to the exceptional and lifelong needs of the child. Most of the parents experience broken sleep, awoken throughout the night to handle their child's need for a position change, to check in on a happen stance noise that woke them from their sleep, or to watch over and care for their child as they seizure. Julie talked about her broken sleep,

> *"I usually just stay up until midnight. I just read from 10:00 to 12:00 because I know he's going to wake me up. And so I get up at midnight. I go move him. And then he usually wakes me up sometime in the night between 2 o'clock and 4 o'clock and then I get up again and go reposition him and get him comfortable. And then I usually can sleep after that until my alarm goes off which is 6:30" (Julie)*

Hannah discussed why a parent cannot simply sleep through it,

"Last night was a good night. I think he woke up, like, twice. And his wake-ups are typically like-- he'll kind of yell, scream, and he arches all the way back, and I just kind of reposition or sit him up, do something, and then he'll fall back asleep. He never fully wakes. It's just like, would you like to lie in the same position all night?" (Hannah)

while Josh talked about how much worry, fear, and frustration can come from this lack of sleep, especially during times of severe illness.

"I remember getting zero hours of sleep because I was worrying that he might stop breathing, and then as soon as I did doze off, the alarm [oxygen monitor] would go off and my wife, or myself, would get him, but we would both get up because the alarm was so loud. I remember I was laying there with [Thomas] awake, and he was still crying, and I remember I was just grunting and screaming to myself just for no reason just to let out some anger, to let out something." (Josh)

These parents expressed that the day begins with fatigue as the parent awakes; the responsibility continues without end. Starting the day is not simplistic, but instead consists of what others might consider 'work'. Some parents talked about how they organize and deliver medications through a gastrostomy tube; delivering both life sustaining medication and nutrition to feed their child. Some parents express that they

have ventured away from the dietitian's recommendations of bottled meal replacement formula due to concerns about the fructose corn syrup that is used as the primary ingredient in such formulas. Some parents have gone to self-blended diets for nutrition, and many have ventured to the ketogenic diet in hopes to reducing the life altering seizures of their child. Zach said it best when he talked about his experience in finding the best diet for his daughter, Emily, and the struggles he had in advocating for her dietary needs with the healthcare providers.

> *"For a long time when we started tube feeding [Emily], she was still on formula. You look at the ingredient list on formula, and I wouldn't want to have to subsist on it. That's what you're going to do is you're going to subsist… Yeah, and fructose. So basically, it's corn syrup and some grain products. She has to be careful with her dairy, so it was dairy proteins that had been broken down to their basic amino acids and stuff. And going back even further than that when we first started feeding her standard baby formula, a half hour after feeding she would just start screaming and arching her back and it was obvious that she was in discomfort. And we brought this up and the doctors' pooh-poohed it and said, "Oh, it's just neurological damage that she sustained that's causing her to be irritable." It's like, "No. Most of the time she's a peach." You feed her, a half hour later-- and this kept going on. I finally was like, "[Jean-Zach's wife], go out and buy some soy formula." Because I had issues with dairy when I was a kid. It would give me a bloody nose if I drank more than a glass a day. I said, "Maybe she's got some sort of intolerance to it. Let's try it once." Gave her soy*

formula, no problems. A-ha. So, we went to the doctor, and he was like, "Well, we don't want to feed her soy because it could hurt her kidneys." So, they came up with a different formula with the broken-down proteins in it. Worked great. We got so much pushback on that, and it took-- It was like, "Hey. There's a problem here." And they pooh-poohed it. And this was kind of an eye-opening thing. It was like, "All these doctors, they've got a lot of education, but they are not perfect. They do not know our kids like we do." And that really showed us that we need to be advocates for our kids. So, we gave her the formula for a while. And it was like, "This stuff really isn't very good. And long-term, it's not going to be good for her to be on this for the rest of her life," ... So, my wife started looking at a blended diet where basically you take your vegetables and your meat and whatever you're going to put into it and you put it in one of the really high-powered blenders. We've got a - oh, what is it? - a Vitamix, I think. We got one of those, and we made up our blend. And when we were doing that [Jean] tried working with the dietitian. I believe it was the pediatric or no the developmental pediatrician. And this lady was like, "Well--" her biggest concern was that we were going to give [Emily] food poisoning… It's like, "We have managed to feed ourselves--" we'd been married at that point for 12 years [laughter]. Like, "We haven't even made each other sick, so…. And then it was like, "Well, we have to come up with a special--" blah, blah, blah. And it was like, "Well--" we were just talking about [Nick-twin brother] eating by mouth. If we feed him chicken nuggets and a couple of orange slices, are you concerned about his dietary requirements? How about just any other kid off the street who's

just eaten whatever their parents can get them to eat because kids are fussy? Are you all up in arms about what they're eating? No. [Emily], at that point, was getting a far, far better diet than anybody else on the planet because it was spinach and kale and oranges. And we were growing our own chickens. We've got fresh eggs, so we put a bunch of eggs in there. And whatever fruit was available and blueberries. If you were going to market something to health nuts, this would be the stuff, and that's what we were feeding her. And all of a sudden, her hair started growing really fast. Her fingernails got thicker and harder and they grew like crazy. Her skin looked better, and she started perking up. And it was like, "Wow. This is amazing." And still, we got flagged. It was like, "Oh, I don't know. We've gotta look at it and make sure the calories--" like, "Well, we can look up the calories for her food and weigh it and put it in here. We know what we're doing [laughter]… Yep. This was far enough back [when] there was a lot of resistance to it. And now all of a sudden in the last two years, it's this huge trend." It's like, "Oh, we really need to look into this because it's doing great things." Like, "Duh. We've been telling you this for--" (Zach)

Julie also spoke about her attempt to find the best diet for her son, Jack.

"We also discussed changing his diet to blended real food instead of commercial formula. I am excited about this change, I have spent hours researching different diets for him, consulting his dietician, and reading other parents stories. I have

chosen the food I want to go with, and have confirmed insurance coverage and a vendor. I just needed the doctor's blessing, and now we have that. I am hopeful that this change in diet will make him feel better and possibly be able to reduce some medications." (Julie)

The parents contend with the timing of delivering dosages of medications to combat seizures, constipation, hypertonicity, leg spasms, and drooling. Mark talked about the frequent adjustments that needed to be made, where medication timing and dosing is as much an art as it is a science.

"We could adjust the timing of the medicines? It's been really a give and take with the timing of everything to try to get it so that he's able to sleep through the night. And so just timing those so that he's awake the next morning. So that seems to be kind of the sweet spot when he needs to have his medication." (Mark)

The day continues with dressing and the struggle that ensues when trying to put a stiffened limb through clothing. Many parents also discussed the always present changing of diapers. What they call diapers is distinctly different than the courteous term used by health care providers; briefs. The parent does not mask what they mean. Their child will never grow out of the diaper phase, will never stop needing the same care of an infant.

“So we've gotten better-- or I've gotten better, I feel like, at getting everything together, but he's in diapers so it's diapers. He has a G-tube so it's food. Depending on how long we're going to be out for-- so I need to make sure-- it's kind of like an infant.” (Hannah)

“There's things involved that are very personal. [Jack], he normally has his bowel movements at night, so that's usually when we're changing poopy diapers. But occasionally, there's a morning poop and it's always a surprise and it's always when we're running late that I go to change his diaper and I'm like, "Whoa. We're dealing with poop. This takes longer." Because I have to clean him up and usually the bed's a mess. Everything has to be done. So that adds a good 15, 20 minutes to my morning time if I have to change a poopy diaper. Like I said, since we don't know what's going to happen, it's always that day when you're running late. You're like, "Okay. I'm just going to quick change your diaper." And then, "Crap. There's crap here [laughter]." So [I] change the diaper.” (Julie)

“And then we'll take turns, I think, between [Britta] [older sister] and myself doing different PT and OT things with her in the morning--for the day, and then I'll get her dressed, change her diaper. She's pretty tight, so it is kind of a

process to get her dressed. So yeah. Then we'll get her dressed for the day." (Kim)

Many of the parents talked about how they did not choose this life, but rather the life chose them, their child, and their family.

"I didn't choose this. This life chose me, and I'm going along with it. And I know that there are people who couldn't. I know that there are people who have to give their child up because they can't do this life. They really can't take care of a child who needs as much as he needs. But there's something about loving him so much that you would do anything for your kids." (Julie).

"He was my first baby, so I was just happy that he was here and alive. And, so time went on, and he ate through a bottle for a while, and then he had to stop that because he was aspirating, and it was going into his lungs. We learned that later though, but we found out the news that he had PVL. And the doctor who told us was really crappy about telling us... I know that we've just had really-- I don't know. It was just not a good way to tell us, I guess. He said he had PVL, and I didn't know what PVL was, and he said that it could later turn into cerebral palsy. He said it was just dead matter in his brain or something, a cyst or a white matter, and I remember thinking, "Why did this happen to me? My son

was supposed to be a professional athlete. His mom was a collegiate athlete. His dad was a collegiate athlete, and he was going to be a professional athlete," was my original thoughts. And I remember thinking a lot about what other people would say because they had already been talking about, "Oh. You're having a boy. He's definitely going to be a pro athlete with you two guys," so I was really excited about having a boy… And then I found out that news. I remember I cared a lot about what other people thought, and I went into my car. First, I beat up the elevator, and the security guard thought something was wrong with the elevator, so he ran over and checked everything out. I tried to get out of the hospital as quick as I [could] without [Sandra] [wife] because [Sandra] probably wanted to be by herself. Her parents were there, and I didn't want to make a scene in front of everyone. So, I went into my car, I remember, and I cried like a little boy who was-- I don't know, who had lost something important to him. I don't remember crying ever that hard and for that long in my life. To learn that my son could be physically handicapped and mentally handicapped, I remember it really struck home to me, and I called my dad later when I calmed down a little bit, and I cried then. I got my church together, we gave him blessings, we did everything that we could to try to fix him and make him better and make him grow up healthy and walk and talk and whatnot… But moving forward, he didn't, but we finally got him out of the hospital, and you never know. You don't really know, not even within the first six months-- we didn't know if he was going to be okay or not, and we took him home." (Josh)

Many parents spoke about their own spirituality and how the love that they have for their child allows them to transcend the difficulties that come from their child's adversity. Where other people might see their child's disability first and foremost, these parents repeatedly talked about how their child is a human being first and saw them as a gift from God. Their child is in fact a real human, in many ways more human than most, authentic to the daily experiences of want and need, good and bad, love and like, as the emotion of hate is rarely expressed. This type of humanness in one's child brings the parents closer to their spiritual God. In some ways a deity of God, expressing his reciprocating love and care with the parent.

> *"Well, I mean, I've always looked at it as he's our gift from God. And it's just our job to take care of him because of the reason that he's here—" (Tricia)*

> *"I had two babies that I had to give back, so even on the worst of days, I never, ever lose that gratitude that I can hold my children and I have that privilege of being the one to give them the best life they can have. Yeah. Even on the worst days, even on the days when I cry all of the time, that core of me knows that God gave me these children for a reason and God gives me the strength every day. That whole quote about, "Oh, God never gives you more than you can handle"? Bullshit. He gives me more than I can handle every single day, and it took me a long time to understand that the reason God does that is because he wants me to lean on him. He never intended for me to do this alone. He never intended for*

[Kevin] [husband] and I to do this alone… Yeah. And that is actually kind of a recent revelation I had is that God did not intend for us to do this alone. [Kevin] and I are very independent, we're always the ones who are doing and giving and helping, but God did not intend for us to be those people when it comes to our children. He blessed us with these children, he also humbled us with [Alyssa] [daughter with cerebral palsy] and Chase [Alyssa's twin brother], and He is shaping us every day into the people that God wants us to be and part of that is the humbling and the learning to accept help and learning to ask for help. That's been really, really hard." (Hope)

Many parents of children with severe cerebral palsy begin their existence as parents of children with severe medical complications. Upon reflection, every parent except for one in this study had their first parenting experience as one troubled with a severe medical crisis. The one parent that did not experience this had adopted her child.

Many of the parents reflected on traumatic past events that linger as continuous, lifelong worry. Some parents understood early on that something was either not typical, or just plain wrong with their child's condition. Some even suspected it before the child was born.

"I knew before [Jack] was born that something was wrong. I mean, I know that

we're not supposed to say that in special needs land. We're not supposed to say what's wrong. But that is how it felt. Something was wrong. He had a brain aneurysm that they detected in utero and they were not sure if he was going to survive. And so, there was a lot of feelings that came with that, but never once did I think that, "Oh, that I don't want him." My thoughts were always, "Oh. How are we going to do this? What do we need to do? What doctors do we need to see? How do we handle this? What do we need to do to make him survive? And he is coming home with us." (Julie)

Once the child was in this world, the signs and symptoms that things were not well were evident. Children were born early, on life sustaining equipment.

"They literally followed us out of the hospital and followed us into the door here… We had these DME people, our nursing company had to come in and do an intake… that day was absolute mayhem." (Hope)

Medical specialists were called in and often provided confusing or untouchable words of dispassion. Parents prayed and cried for their newborn that is fighting for their life. As long as the baby fights, the parent fights too. Nurses show compassion by helping the parent learn to touch their baby for the first time. Many of the parents see this gift of life as a tangible sign of God's love. After speaking with these parents, no one could

disagree with this idea, that these children express love, and continue to bring about the humanness and connectedness that all who truly care for their children bring together. Hannah said it best when she described how she received the news of her child's diagnosis, periventricular leukomalacia (PVL)- a diagnosis that is sometimes paired with cerebral palsy.

> *"So we got his diagnosis at a month old. His actual diagnosis is periventricular leukomalacia. So his first summer, I was fine. The MRI at a month old is what showed the PVL and, I mean, that was a very traumatic day. But as far as physicians and doctors, we have mostly been very lucky to be-- I've weeded out the ones that are not because at the beginning we were seeing-- I mean, we were going all the time to specialists, but that particular neurologist had zero bedside manner. I'm like, "You forget that a parent is hearing this information for the first time. That you're telling them this life-changing information. You might say it to this-- you're saying it to me and then you're going to-- and then in an hour say it to somebody else. And you say it multiple times probably in your career, but I'm hearing it for the first time so you need to watch your delivery, as a parent, on how you are expressing yourself." (Hannah)*

Parents of typically developing children watch their child grow and watch them mature and meet new milestones. The milestone of watching a typically developing child lift their head is quickly forgotten as the child sits upright and eventually walks in what

seems like the blink of an eye. And yet some of the parents in this study basked in the milestones that others take for granted. When a child with severe cerebral palsy reaches the age of 10 years, the accomplishment of rolling is a repeated, cyclical success. The child may have demonstrated this skill at the age of 4, however, in a growing body, the shear mass changes the forces needed to complete the movement. And so, again, at 10 years of age, the parent is elated in the child's success of once again being able to roll their now 10-year-old body over; if not for pleasure, also for comfort. Hope and Zach talk about how these skills are often taken for granted in neuro-typical development, but to these parents it is a big success.

> *"Well, with a "normal kid", "Oh, they rolled over today. Woo-hoo." With [Alyssa], we're talking months, if not years, of physical therapy, and its hard work for her, it's a big commitment for us, but those little things that so many parents take for granted are miraculous for us. It's just you don't take anything for granted with these kids. You're grateful for every day that you're blessed to spend with them, and I honestly don't know what it's like to parent a neuro-typical child, but it's just rewarding on such a deep level to be able to-- to be privileged to raise a child like her, I guess." (Hope)*

> *"Independence. It's one of those times where she's not completely reliant on somebody to move her somewhere. The same thing with floor time. She can get down on her tummy or on her back, and occasionally roll over, but she can scoot*

herself to where she wants to go and interact with somebody of her choosing, and that makes her happy." (Zach)

The burden that the parent holds is not only to carry their child, but also to lift their psychological load, to help their child live life. While other 14-year-old boys are complaining about mowing the lawn, Mark talks about how his wife, Beth, one day took their 14-year-old son Brady, into the yard. Beth lifted up his arm and placed his hands-on top of the lawn mower handle. At this point the arms would resist as excitement and tension builds in his body. Beth wrapped Brady's hands around the handle and squeezed, allowing the lawnmower to vibrate between his fingers. Mark basked in the excitement that his child felt; to allow his son to have the confidence and pride in being "useful" by mowing a swatch of grass, exhilarated and uninhibited by their body, and to allow Mark and Beth the ability tell others 'My child mowed the lawn today'.

[Researcher: What does your child need to have a fulfilled life?]
"I guess the feeling like he's useful, maybe. I remember sometime after we first moved into the new house up there and [Beth] had the push mower out. And so, she rolled [Brady] up behind there and got his hands up on there. And so, she was-- as much as she could, pushing the kid in a wheelchair with the mower in front. He is feeling useful. And the program that they have at school and the Coffee Club where he participates in the mornings and stuff like that. They actually get coffee. They deliver to classrooms. And so, part of what he is able to do is they have them kind of clean the tables. So that's part of his job. So, he's

participating and feeling useful and things like that. I think that part is the fulfillment that you have a quality of life, that you're able to make a difference, maybe. It's kind of hard to explain. And for him, it's fairly limited." (Mark)

The parent enjoys the time spent with their child that is not associated with their medical care, but rather is to help their child grow and develop. The parent considers their role in their child's development. They consider their role in teaching their child social skills, a form of pedagogical tact. They balance the need to teach their child not to scream when another child is playing with a toy, or cry around unfamiliar people, while at the same time giving way for the child's disability and difficulty with communication.

"So there's a fine line of making way for his disability and-- I still want to treat him like a five-year-old. I still want to teach him how to share and that it's not okay to scream his head off just because somebody's playing with a toy. But there's a fine line to where he's inconsolable. We're going to stop trying to teach him at that point. Let's just walk away for a little bit and let him get himself together."(Kelly)

[When talking about her child's social anxiety]

"It's so important because he was not having it when he was little. You couldn't take him anywhere, put him anywhere around people, and him feel comfortable.

He was not. And it was crossed eyes, arms out, like, "What is happening around me?" And now, if it happens, you can usually talk to him and reason with him, and say, "You're okay. People want to talk to you," or, "They want to meet you," or, "This is where we are." I guess, it is kind of a level of anxiety. It calms him down, so I think that constant talking to him, which we all do all the time-- I think it's so important to constantly communicate what is happening." (Hannah)

All of the parents speak to how they are always available for their child, always thinking about their child, no matter how old the child is. Their child always needs a guardian on call. Because of the ongoing and daily medical care, the child is always at risk of needing more formula, a gastrostomy tube replacement, more diapers in their bag, or a change of clothes. The parent may leave the child during the school day; however, the parent is always on call. The risks associated with seizure activity require immediate attention and rapid decision making. Not being available is not an option. Sometimes a parenting couple will work it out between one another, determining on a daily basis who will be on call and when. Even small decisions become big issues if the child misses out on something. The children rely on people who care about them because without a reliable and sensitive caregiver, these children do not have a voice.

"I always have to make sure. [Michael] is not in a position where he will ever be able to be unattended. There will always have to be someone in charge of him." (Tricia)

“When she is in school, my cell phone and the house phone are never further than an arm's reach away from me - if I'm outside, they're both in my pockets; if I take a nap, they're both on the nightstand; if I'm in my crafting area, they're both next to me - and if the phone rings and that caller ID comes up with her school, I'm, again, instantly into adrenaline, and then when I hear the nurse's voice on the other end of the line, it really hits hard because if school is calling me, it's usually because she's having a lot of seizures or not doing so well.” (Hope)

“But then it's not over because I'm on all day. I have the phone next to me. If the school calls, texts, I have to be there to answer it. And in elementary, he had a lot of seizures at school. So, they would call, and I would freak out because I knew it was a seizure. So, I'd answer, and they'd say, “[Jack] is in seizure. We're two minutes in." At four minutes, they had to give rescue meds. So, if they gave rescue meds, I would have to go to the school and sign off for the ambulance to do whatever. Either they're taking him to the hospital, or I'm saying, "I'm taking him home and he's not going to the hospital." So, there was a lot of times when I just had to get up and leave work with a seconds notice. And I'm a half-hour away from the school, so it would take a half-hour to get there. And so that was hard.” (Julie)

The child with severe cerebral palsy has significant medical concerns. Many of the parents will see specialists for all types of medical issues. Parents organize appointments. They will travel to see the specialist that best understands their child. Some parents regularly drive up to 4.5 hours to see specialists. To make this work, they try to fit in multiple specialist appointments in the same day. Sometimes these trips will last over a few days. And as the child grows, these trips can require multiple caregivers. Both caregivers are needed for the sake of watching for seizures as the other one drives, and because of the need for a 2-person lift as the child grows.

> *"[Michael] had surgery at the [Hospital Name] in [Midwestern City]. And we chose that because we felt that was the best place for him medically to go, even though knowing that adds those trips up there… It's about 4.5 hours for us. And so, with the surgeries, you have pre-op appointments. And then we try to schedule so that all of them are at the same time, so maybe you have to spend the night up there if they can't get it all in a day. But then also, I mean, just the travel. Four-and-a-half hours up there, a full day of appointments, 4.5 hours back. Depending on how he was, that was just too much to do in a day. So, you figure two days away for medical appointments. And then the days of surgery. So, family came up. So, [Jim] [husband] would come up and stay for part of the time. [Braeden] and [Natalie] [Michael's brother and sister], my mom would come and brought the two of them up for the surgery and then would bring them back. And then once we would get home, we would have, usually the next week, a follow-up appointment. So, drive back up there. And that's another thing. Keep*

going or stop? ...As far as do you make the trip and go all in one day which was a lot for him? So actually, the nurse, traveled with [Michael] and I one time because I can't go by myself. Have to have two adults to go to help with transfers and just to go in case there was something, an accident or something. So, I think we probably had maybe five or six appointments up there in the last six months plus two surgery dates." (Tricia)

"They just tried to put him on one of these-- Topamax or one of those. I can't remember what it was at the time. And so, we were really uneasy about that. We gave him six months to come up with something. And then we got a referral to go to [University Hospital]. That's where we got our answers at. Yeah, because actually, the family that we're friends with, they used to go to this particular doctor over there when they lived over on the other side of that state. And we still see her today."(Dan)

[Researcher:"How long do you travel to go see her?"]

"Usually, every six months. So, it's about three hours." (Dan)

Parents have a lot of appointments and information to juggle. In addition to attending specialists far away, they all attend regular therapy appointments to work on skills and maintain the mobility of their child. Some parents struggle with whether they should or should not have continuous therapy, wondering if they could get by with less therapy as the child gets older.

[Response after being asked if the child enjoys the pool]

> *"Yeah. He likes it, and he also does aquatherapy. So, the only issue with therapies, [Sandra] thinks that they're really important, and I mean, I think they are, but at what point do you just kind of do it yourself? I could put him in a stander. I can help him touch things. I don't know at what point do we stop hippotherapy? The horseback riding therapy, at what point do you stop, or do you just keep going even though he might not ever improve? And [Sandra's] point of view, he's began to kind of like this stuff. He loves the horses, and he loves it. And we like the therapists and things. But I don't know if he's going to get better with all that. And I guess it's-- I don't know how to put it. I think that they're important, especially when they were younger, and we've been doing it for so long. But every once in a while, it's like we take two hours out of a day to take him to a 30-minute horse therapy. I probably could strap him to my back and take an hour out of the day to giddy up around the house or something. I know it's not the same, and I know the importance because—[Sandra] would kill me if I said that [jokingly]." (Josh)*

Other parents are grateful when insurance is willing to continue to cover their ongoing regular therapy appointments. Not all of the parents understand care models such as episodic care, where the therapist regularly consults with the parent and child, and the child has short and repeated episodes of therapy throughout the child's life. Parents are

cautious when ending an episode of care because they are concerned that the child will lose the limited function that they have, or that they will not be able to return to therapy in the future. To the parent, the word discharge means that others do not see the value in their child maintaining their skill to roll, lift their head up, or experience movement. They do not understand different care models and are concerned that the therapist will not continue to aid the child in maintaining their mobility and comfort throughout their life.

> *"[Jack] returned to therapy today after having a couple of weeks off for bad weather. He did a good job, I think he really likes [Jenny], the therapist. Or the afterschool time just works well for him because he's awake and alert. Twelve years of therapy is a long time, I am just grateful that [Jack's] insurance will still cover therapy considering his age." (Julie)*

Some parents discussed how they will often maintain data about their medical appointments using home-made "medical charts" as a way to keep a record of all of the information, diagnoses, and past medical history of the child. The parent will keep track of current medications and dosage amounts or may keep a diary about something that has recently been plaguing the child. For example, if the child writhes with discomfort, the parent may track their bowel movements to try to determine if the child is constipated and requires a change in their dosage of Miralax™.

"We keep a book about [Jack] in the kitchen - about his schedule, about everything he needs and does - so that if she [Julie's sister, who sometimes cares for the child] needs to reference that for something, she can." (Julie)

[Pertaining to keeping medical records]

"Yeah. So, you organize, you've got binders, and you do utilize some work time… One of the most difficult things is trying to figure out what is wrong with [Bobby] when it's clear something is bothering him. The most recent issue we've been dealing with lately is constipation. This has been something that he's dealt with since he was a baby. Over the last week or so it was very obvious that he was uncomfortable and in pain. He'll often have excessive extension or be super cranky and irritable, which is just not his personality. We took him to a G.I. last week and she recommended using a liquid laxative. We tried that for the first time over the weekend. The amount of poop this poor kid had in him was insane. And as a parent you start to feel guilty because you weren't able to identify the problem. No wonder why he had been in such discomfort." (Hannah)

Sometimes medical decisions have to be made that have a significant, lifelong impact on the child. This creates a level of guilt and worry that many parents of typically developing children never experience. Many surgical interventions are permanent. Some children have such severe high muscle tone that they cannot rest their muscles while sitting, lying down, or sleeping. Parents worry about life altering decisions. One parent

remembered the anguish they had over the decision about his child's rhizotomy (a surgery that cuts nerves in the spine). They were in angst because of the concern that they would be taking away movement from their child. Even though they know that their child lacks functional movements, they realize that the movements that the child does have are meaningful and purposeful.

> *"So for his case, when he had the initial first surgery where they're clipping the nerves - and now, he can't move his legs and things like that - one of the things that he was able to do, although it was causing some of the problems, is he was able to lay in bed and he was able to move. And so now, we've taken that away from him, the little bit that he has." (Mark)*

Being a parent of a child with severe cerebral palsy can also include the burden associated with public perception and judgement. The general public's lack of knowledge regarding the causes of cerebral palsy leaves some parents feeling as though others wonder why their child is disabled. Julie spoke about this judgement that comes from other people staring.

> *"And there's something about it that I take personally. I feel like people look at me like, "Oh, what did she do when she was pregnant that she screwed up her kid." And that's hard too because it's a personal feeling. Like, "Oh, she must*

have been on drugs when she was pregnant with that one because he's not okay." There's that thought behind it that scares me that people would think that about me and my family." (Julie)

Judgement comes from unexpected places too. Strangers who set the stage for ridicule cause lifelong hurt. Kelsey recalled being judged about her son needing a shaping helmet for his head.

"When [Jeffrey] was very little, under a year, he had a head-shaping helmet. And [Greg] [Kelsey's husband] was checking out, and I was sitting down and doing something with [Jeffrey]. And this elderly lady was sitting there. And she goes, "Oh. What's wrong with your son?" And I said, "Oh. Nothing. His head's just a little misshapen, so this helmet's going to help him." And she goes, "Oh. In my day, we called that lazy." (Kelsey)

Some parents feel a lack of understanding from their own family members. When a family member does not understand the fragility of the child's immune system, this can lead to hurt feelings. At times, this can cause angst among family members because of what the parent views as misplaced judgment from others. Zach recalls a family member saying, "Well, you're trying to stay away from everybody." And Zach responding "No, I

desperately want interaction with people, but I've got to stay away because I can't afford to get sick."

> *[Speaking of other family members] "They know that the kids are not as strong as their peers, but I think it's just a hard process because it's not something they deal with day-to-day. And sometimes there's a little bit of hurt feelings or whatever because they think, "Well, you're trying to stay away from everybody." It's like, "No, I desperately want interaction with people, but I've got to stay away because I can't afford to get sick." (Zach)*

Parents see that some people struggle with understanding the needs of the child with cerebral palsy. Kelly notices that the wheelchair can be intimidating to some who do not know how to interact with it, causing her child to miss out on opportunities for play and learning that he otherwise would have had if she were present.

> *"On Sundays, he goes to the typical room [church Sunday school]. And he enjoys the music time. And I don't really see what they do. But I know that when I pick him up, he never has the project that they [the other children] do. And so I went to the director a couple times. And I was like, "I know it's difficult. You have a room full of five-year-old's, and maybe, there's not always enough help to get him one-on-one. But I want him to be treated just like the other kids. He*

shouldn't not be having a project." (Kelly)

Parents talked about the most important thing to them is that their child is safe, happy, healthy, and feels loved. They want this from everybody who cares for their child.

> *"No one will ever love him like I do. And the kind of love that you have goes with the care. So, it's not just, "[Jack] needs to be fed, clothed, and dressed. These are his care tasks." [Jack] needs to be loved. [Jack] needs to know you care about him. [Jack] wants a relationship with you. He's not a patient. And so, I am very particular about who gets to take care of him." (Julie)*

Parents discussed their past experiences with home nursing, or stories that they heard from other parents that left them feeling uneasy. These past experiences and the stories from others influence the parent's ability to trust others to properly care for their child.

> *"And to have somebody come into our home at night and watch over our kids while we slept; that takes a lot of trust and some of the nurses we had didn't really do a lot to help foster that trust." (Zach)*

"Well, I kind of have heard or read the horror stories about getting a home nurse."(Kelly)

For these parents, the idea of their child not being protected frightens them. Mark talked about a time that his son was not respected by a teacher, and how it angered and hurt him to see somebody not give his child respect and care.

"So he had a teacher. And apparently, at one point, this teacher had come up and tapped him on the head and said, "Is there anybody in there?" And so probably, had I saw that, he [the teacher] might have ended up with a broken finger. So just protecting him when he needs to be protected, encouraging him when he needs to be encouraged, trying to do whatever I can to make sure that he knows that he is loved, doing everything I can to take care of him." (Mark)

News reports of individuals who are abused scare parents. Parents lose trust in others as they experience and learn more about the different ways that individuals who are not autonomous can be abused. Abuse can come in so many forms, psychological, physical, sexual, and neglect. Parents understand that their child, whether now or in their future state as an adult, are unable to protect themselves. This hinders the parent's ability to see the future of their situation and future care for their child.

"Safe is taking care of him in a way that he is not going to get hurt - not any part of him. Not the fragile parts of him because he's medically fragile and not his feelings. I don't want any part of him harmed. And I don't want him with a person that I don't know and trust. I need to know the people who are involved in his care. We live in a world where there's scary people who prey on people who can't defend themselves. I never want [Jack] in that situation. The thought of something happening to me and [Bill] [Julie's husband] and [Jack] being institutionalized horrifies me… It all comes back to safety. I want him safe. I don't want him to be in a situation where he can be taken advantage of. And that's hard because we all have a self-awareness about us. We know not to walk in a scary neighborhood at night in the dark by yourself. There [are] certain things you know instinctually that you don't do because they aren't safe. [Jack] doesn't have that, and he relies on other people to be the instinct for him, and so I have to trust those people who are being his instinct. I think that's why we just haven't gotten a lot of people involved in his care." (Julie)

"Whatever keeps him happy and engaged. And, I mean, there's all the physical things too. Not having injury, not being abused, not being-- respect for who he is. And I think that's big. I mean, [Michael] knows whether you have respect for who he is or not or whether you get him or whether you don't. I mean, he knows." (Tricia)

Theme 2: Remarkable

"If you can quiet yourself enough to listen, the things she'll tell you without saying a word are remarkable" -Hope

The etymology of the word remarkable comes from the 16th century French word *remarquable* meaning "observable, worthy of notice".[160] To the parent, the child with severe cerebral palsy is remarkable. The parent needs to know that others will listen to their child. The word "worthy" from the 12th century French word *merite* meaning "spiritual credit". Parents talk about how their child is communicating, and that others are challenged to suspend preconceived ideas of how communication should be and actually listen. The parent worries that others won't respect the child or their sometimes subtle ways of communicating. By defending their child's existence, many of the parents talk about how they worry that others won't see their child as they know their child to be; worthy by the credence that they live by that their child is divinely given to them, and to the parent their child represents so much of their own relationship with God. In the theme "Life is Hard, filled with Burden, Worry, and Love" the notion of God captures the concepts of the loving relationship. In this theme, "Remarkable", these statements about God were used to express the worthiness of their child that makes them truly remarkable to these parents. Tricia and Hope said it best when they talked about the inter-relationship between their child and their God.

"Well, I mean, I've always looked at it as he's our gift from God." (Tricia)

"That core of me knows that God gave me these children for a reason and God gives me the strength every day… A recent revelation I had is that God did not intend for us to do this alone… He blessed us with these children, he also humbled us with [Alyssa] and [Chase] [Alyssa's twin brother], and He is shaping us every day into the people that God wants us to be and part of that is the humbling and the learning to accept help and learning to ask for help." (Hope)

Parents see their child as worthy of notice; to see and to understand their child. Hope said it best when describing her daughter Alyssa's communication style, she referred to Alyssa as being "a quivering mass of emotional antenna." This powerful statement brings to mind the art and skill of amateur radios, known for their large antenna and dials that are mostly used by radio hobbyists. These radios are often used as a way to communicate with other people across the globe and can be implemented as a last resort in emergency situations because of the reliance on analogue radio waves. The listener sits quietly and patiently, deciphering the correct turn of the dial to connect to the signal. A static babble of scratches and squeals are heard until a faint voice is perceived. The listener stills their body and brings their head closer to the receiver, even though the headphones are as close as they can come. The dial is slowly turned, back, and forth as

the listener tunes into the signal. This signal carries words with meaning and purpose. Sometimes a connecting “hello” and other times a resounding request. And in some cases, the signal sends out a distress call asking for help.

> *“[Alyssa] is a-- I don't even want to say a [little] bit; [Alyssa] is an empath. She picks up on feelings and internalizes them, but she also projects her feelings. If you just hold her and empty your mind, you will know what she is feeling. My husband refers to it as she's a quivering mass of emotional antenna. If you can quiet yourself enough to listen to [Alyssa], the things she'll tell you without saying a word are remarkable.” (Hope)*

The parent understands that to unravel the needs of their child, they need to be quiet in their mind and body as they listen. Listening requires the parents to be open to the child’s worldview, surrounding their thoughts with the child’s observations, sensations, and perceptions. Parents talked about how they look at the child’s facial expression, listens to the sounds made by the child, and watch their body for movement, tensions, and intentions.

> *“For [Michael], it is what he's looking at or what he's trying to get me to look at, whether that's looking at it with his eyes or making noise. It is the look in his eye. And I don't know how to explain that part other than I just know my kid, and*

it's how you just know your kid when you look in their eyes. It is his facial expressions which can be pouty, can be smiley, can be-- he's really serious which can be-- I don't know… He shuts down. If he tries to engage you or if you don't acknowledge him communicating to you, he will wipe you off the slate. I mean, he will shut down, and he will just be done putting forth the huge effort it takes for him to interact with you. He might give you a little bit of time. When school first starts, he might give them a little bit of time. But if it's repeated and repeated and repeated, he's just going to shut down. And the way he does that is he just doesn't respond. He doesn't look at you with his eyes. He just doesn't respond to you and do what you're demanding that he does." (Tricia)

"And sadness, … That's when the bottom lip does a mega pout, and she does that. Yeah. There's a definite difference in sad cry as opposed to, "Well, I'm kind of lonely here on the floor and somebody needs to pay attention to me," cry. And the, "I'm hurting," cry is more of a frantic sign." (Zach)

These raw, analogue signals inform the listener who chooses to listen. Parents discussed how time and space interplay with their observations. Knowing where their child's mind and body has been, is, and will be plays an important role in connecting the heard and the perceived.

“I think that last phrase-- so with [Alyssa], you have to make inferences. With [Chase] [Alyssa’s twin brother], he directly tells you. With [Alyssa] and other children similar to [Alyssa] in their situation, you have to put work into the fact of saying, "I see this, I'm interpreting this, and I'm going to infer that this is it, but then I'm going to do a checks and balance to see if I'm right." That's a very analogous way of trying to say this step-wise, and I don't want to say it takes effort because, certain personalities, that is connecting, you know what I mean?” (Tricia)

“The other night, he was already asleep. I had [Bobby] and [Polly] (Bobby’s little sister), and I was putting them in pajamas, and [Polly] said to me and [Bobby], "Can I push [Bobby] around in his chair?" and I said, "You can before you go to bed. Let's get in pajamas first. So before we get on the couch, you can push him for a little bit in his chair. Okay?" I forgot. We were on the couch. It's time to go to bed. I didn't put him in the chair. Whining, upset. Couldn't figure out what's going on. Figuring it out. Thinking in my head, "What did I say? Why does he not want--" because, generally, he knows we get on the couch. He lies on his pillow. It's time for bed. What is it? So, I said, "Oh. Do you want [Polly] to push you in your chair?" And his yes is usually legs kicking, smiling to know that that's what he wants. Well, that was what he did. And I said, "Okay. You can go in the chair now, [Polly] will push you around for a little bit, and then it's time for bed." He was fine after.” (Hannah)

Rest assured, the parent knows and talks with absolute certainty that their child is actively communicating, responding, and engaging in their relationships. The child expresses their emotions, wants, and needs.

> *"So if he [Bobby] is awake, he knows to let Jerry [Bobby's father] know when it's time to wake up so he'll yell for him like this [laughter]" (Hannah)*

> *[Researcher begins: "So you say something's wrong, does he ever exhibit frustration that doesn't have to do with his body, doesn't have to do with feeling bad?"]*
> *"Yeah. When he doesn't like what's on TV. He gets real whiny." (Dan)*
> *[Researcher: "How do you know it's because of the TV versus-- how do you differentiate it's the TV versus his ears?"]*
> *"How do I-- because he's just non-stop whining when it's his ears. But when it's the TV it's-- all's I got to do is switch the channel." (Dan)*

Understanding a child's social and emotional needs is complex. These parents talk about how they have to understand the child's daily lived experiences to be able to meet their child's needs. In addition, these needs are intertwined with development of a human that experiences the world in complex, and atypical ways. Josh spoke about how sometimes, when it comes to meeting his child's emotional and social needs, he sometimes has to run down a checklist with the child, attempting to give the child relief

from their inability to speak. Kelsey spoke of how listening to her child and knowing about his past, present, and future helps her to better understand the needs of her child. The ability to understand their child on this level requires patience, reflection, and an understanding of the child as being.

> *"Say he's sitting down or sitting in his chair, he'll start getting upset, or sad, or whatever the case may be, whiny or something. And then we'll say, "What do you want?" And we'll go through that list a lot of times. Do you want to go outside? He won't want to go outside. He won't make a move of excitement or anything like that. Do you want to play the guitar? No. He won't have any movement. And then sometimes it breaks down to, "Are you okay? Does something hurt? Does your tummy hurt? [Do] your arms hurt? Do you have a mosquito bite? Are you hungry? Are you thirsty?" And then it's kind of figuring out what's going to get him back to "[Thomas], is the issue there?". And then sometimes he just wants attention. Mom will be cleaning the house or something like that and he just wants attention, so he'll just whine until you have full attention on him. At school, that's one of the big things that he does there. If they are doing stuff, the kids at one station, and [Thomas] wants to do it and he's not in that station…" (Josh)*

> *"Usually, I think about what he's done for that day. If he's had a busy day at school, if he's been on the road, or he's been physically doing a lot, like for*

multiple doctor's appointments, or if he's been-- if I'm wondering if he's sick, usually I'll go through a checklist in my mind of, is he messing with his ears? Is he coughing? How did he sleep? Has he had a BM? Has he eaten well? Does he look like he's breathing funny? So I usually will go through stuff in my mind to think of, "Okay. Are we upset? Are we hurt? What's going on?" (Kelsey)

Many children with severe cerebral palsy require time, patience, and care. The parent understands that the child lives in a society that values fast pace, efficient, easily-intelligible, and fleeting ideas, thoughts, and conversations. The parents are concerned about one societal inevitable outcome; that their child will be dismissed and not heard by those who are supposed to care for the child.

"[Chase] [Alyssa's twin brother] is a ray of sunshine wherever he goes, and to get to know [Alyssa], you have to quiet yourself, you have to pull in, and you have to pay attention, and people tend to like the easy with [Chase] and overlook the harder with [Alyssa] and if somebody does that, that's one area where I really struggle to give grace to people is if they focus on [Chase] and not [Alyssa]. We don't do that favoritism. So for me, the hardest aspect of trust to find is somebody who sees [Alyssa], who can appreciate the fact that she is just as smart as her brother, that she wants to interact, she wants to be included, you just have to work harder for it." (Hope)

They have seen this dismissiveness in front of their very eyes. When a physician, teacher, nurse, therapist, caregiver, or family member does not take the time to communicate to the parent, they quickly conclude that this individual will never take the time to communicate or understand the importance of their child. Even with the best intentions, someone can be too quick not to live in the present moment with their child and not see that child for the awesomeness that they truly are to this parent. Dan said it best when he felt that the doctor was willing to try different medications, regardless of if those medications caused the child to "pass out".

> *"[the doctor] made us really uneasy. And he always seemed to want to do is put him on these bridge medications that made him pass out." (Dan)*

The physician, teacher, nurse, therapist, caregiver, or family member that has the ability to be still and present for the care of their child is the one who is most likely to connect to this parent and their child.

> *[Explaining why she likes her physiatrist] "Well, she really takes her time with [Bradly] and talks through things. And, I mean, she looks at him with his AFO braces on. And she looks at him with his AFO braces off. And she looks at him in*

his wheelchair. She is so thorough with him to things that I wouldn't know." (Kelly)

The parent notices those people who are open to helping and to being present. These people are scattered throughout the world; in hospitals, therapy clinics, doctors' offices, grocery stores, and restaurants. To the parent, these people are like hidden gnomes, a legendary dwarfish, human-like creature that guards the treasures of the earth.[161] Like hidden gnomes in the forest, these people pop through to wave a friendly hello and then carrying on, they move back behind the trees. These individuals hit the mark, communicating with the child by telling them a calm "Hello!" squatting down next to them to look at their face and holding their hand to greet them. The parents talk about noticing the child enjoying this interaction where another human acknowledges their individual-ness, their claim as an entity, as being. The parent knows that this person stopped, if not only for a moment, to see and meet them as they are.

"A lot of them don't know what to do, they really don't, and it helps when I tell them [Alyssa] loves to say hi, she understands everything you're saying, but she can't respond back. She loves, especially, when children come up and talk to her and hold her hand, so it's a lot of explaining to people because she is smart, and she gets it and she understands when she's excluded and that hurts her." (Hope)

These hidden gnome-like people do not always speak. In fact, sometimes they do not even stop by to say “Hi”. Sometimes these people present themselves as a stranger in a restaurant hidden from view only to know about them when the parent asks for the bill and the waitress says, *“Somebody already took care of it for you!”;* as was remembered by Zach when he spoke about how “*in this area [around his home] people are wonderful.”* This simple gesture is meaningful to the family and expresses a deeper heart-felt sentiment of ‘I don’t know what you need, but I know that I support and care about you.’

Other people address the parent, not sure how to include the child but acknowledging their importance to the life of the parent. Sometimes these conversations are filled with incomprehensible thoughts and questions like, “Is he going to get better?” A complete lack of understanding what cerebral palsy is and means. The parent understands that these people are trying to understand and make sense of their life, both the parent and child’s, and their own.

> *“I find that people are supportive of us but don't really understand the life of raising a child with a disability. Even my own family sees him on FaceTime, and they see him sporadically. So not that they're shocked when they come and see him, but, sometimes, I'll get questions like, "Oh, he's going to get better?" They don't really understand cerebral palsy. They think that with enough physical therapy, he'll get better. And I've tried to be very blunt with them and tell them like, ‘He may have some improvements in mobility, but he's probably never going to talk and probably never going to walk.”(Kelly)*

Parents also express how they see other people in the public struggling with how to talk with them and their child. The struggle is seen when other people tell their own child not to ask questions about the disability that is seen in their child. While the parents want people to see their child before they see the disability, they understand that children are curious, and these parents want to educate others on their terms.

> *"We went to Disneyland on a Wish Trip. And this little girl, who was probably about seven, asked us why [Alyssa's] eyes were up towards the ceiling. And I explained to her. I said, "Well, because she does not see very clear straight ahead. So if she's looking up, she's trying to see you clearer." And the dad said, "Oh. You shouldn't ask her questions." I said, "Nope. That's okay. Have her ask anything. I'd rather her ask and have an answer than to be curious and thinking, 'Well, what's up with that kid?'" (Hope)*

Another important factor that is worthy of notice to these parents is that their child does experience pain, and for some children pain is ongoing. Tricia spoke of her child's pain prior to having hip surgery:

> *"I think it [referring to pain] was just an ongoing, constant experience that he had." (Tricia)*

Parents express that discerning pain from emotional distress is intuitive to the parent, understanding that their child does have pain. Parents talked about how understanding their child's pain is important, discernable by observing the child's grimacing facial expressions, "contorted" and "tight" body movements, and painful cries.

> *"I just know. I just know when something's not right. When he is in pain he will be upset, and you can tell he's in pain… So, he has spasticity in his legs, so clonus, and so sometimes he has spasms that hurt and he will cry about that, but you can physically see his legs shaking so you know that's the thing that's causing him the pain. It's just a matter of looking at him and trying to figure out where the pain is." (Julie)*

> *"Well, you can generally tell by the look on his face that something is wrong." (Mark)*

> *"Contorted. Yes. Just being contorted. And you could put your hand on those muscles and just feel them. They were like ropes. They were tight. And they were miserable. And it's like if you would take time and just rub it for him, he would kind of just relax. But it wouldn't ever last. It was just while you were doing it." (Tricia)*

While these parents know that their child experiences pain, simply knowing that the child is in pain is not enough. Josh spoke about how difficult it can be to understand his child's pain because of what many parents refer to as their child's high pain threshold. These parents understand that their child experiences a lot of pain and discomfort in their life and want to catch the cause of the pain before it becomes a bigger issue. Josh, Hannah, and Kelsey said it best when describing their children's pain tolerance.

> *"Well, the way that he acts, the way that his face is. And the funny thing is [Thomas] can tolerate a lot more pain than anyone else. And I feel like the reason he can do that is it's not necessarily he has learned or knows that that's pain. My observations is it's a different feeling. So, a shot at the doctor, sometimes, he won't cry at all or anything. Sometimes if maybe [Jon] [Thomas' toddler-age brother] falls on him or hits him or sometimes …his heel will get scraped up. It makes me sick that I didn't catch it. But it doesn't register as so much pain to him. It's a feeling. It's a different feeling that he's not used to. So, he doesn't know exactly to cry about it. So, we have to be really careful to watch what's going on with his body because he doesn't even know… It's just a feeling of discomfort maybe or something… And sometimes he just won't cry. (Josh)*
>
> *[Researcher: "When he doesn't cry, how do you know it's pain then?"]*
>
> *"Because looking at it and how, maybe, hard he hit it or how that would hurt me. Like his heels scraping on his [foot rest]— it got really bad-- We hadn't noticed and it was right on his Achilles tendon. And he just would never really address it. And... it was bleeding before I really recognized it. And I was like,*

"That's pain. That's pure pain that I know is pain," and he'll baby it a little bit…" (Josh)

"I think his pain tolerance is very, very high. He was in [the] NICU [Neonatal Intensive Care Unit] for two months. I think with every-- I mean, that's my rationale. Everything that they did to this little itty-bitty thing at that point has made his pain tolerance insanely high." (Hannah)

"Yeah. He's a tough kid." [speaking about her child's pain tolerance] (Kelsey)

Connecting to the child does not always equal understanding the child. This analog method of communication is sometimes difficult to read, especially when pain can be caused by so many different issues. Julie described this complex judgement of pain when she said the following:

"I just know when something's not right. When he is in pain he will be upset, and you can tell he's in pain. What you cannot tell is where it's [the pain] coming from. So, there's lots of choices. Could it be his tummy? Is he having digestive issues? Is something not settling well in his tummy? Does he have a headache? Because he has a lot of brain stuff going on, so headaches would be par for the course for his diagnosis. But if he does have a headache, what does that mean? Do I just need to give him some Tylenol and then he'll be fine or is this 'we should call the doctor' because there could be shunt malfunction or something

else that's going on that's bigger than just, 'I have a headache'?" (Julie)

Theme 3: Identity Transformation and Empowerment Towards Authenticity

The parents identity transformation moves them towards an authentic life. The parents' identities are transformed through their child's fragility. Having and loving a child with severe cerebral palsy is transformational. It is also impactful on relationships with other people. Typical childbirth and having a typical newborn baby are emotional events filled with wonder. Beginning parenthood with a significant medical crisis still has its wonder, but this wonder is paired with fear and worry.

Many parents of children with severe cerebral palsy described their first parenting experiences through medical crisis: premature birth, breathing and feeding tubes, intravenous lines, magnetic resonance images and brain damage. This initial medical crisis was weighted with such deep sorrow and worry; the worry comes from the child's unknown future and not knowing what to expect. Will their child live? Will their child grow and develop? These questions are foundational in creating a pathway of transformation for these parents.

"I think about just the trauma to myself as a mom with him being born by emergency c-section at 28 weeks. Just that knowledge really, I think made me very cautious as a parent when it comes to the medical field maybe. And so

looking back, I feel like I had a lot of trust prior to [Michael] being born and then after he was born, it takes a lot for those doctors or any medical provider actually to gain my trust in order to trust them enough to make medical decision on [Michael's] behalf." (Tricia)

"In the beginning, when he was born, he was obviously a medical emergency. So he was born at [Local Children's Hospital]. He was life-flighted to [University Hospital 90 minutes away]. He was treated there. There were no choices because it was an emergency. We were at the mercy of what the doctors told us was best." (Julie)

"[Thomas] was born a preemie at 28 weeks, and already I was nervous. I remember when they said that [Sandra-Josh's wife] was going to have him at 28 weeks, it was our first child, so I didn't know really what to expect." (Josh)

Coming home for the first time as a parent after months of living in the NICU, they found themselves busy with caring for their infant. Hope talked about their first day home with their twins.

"[Alyssa] came home on oxygen because her lungs were so underdeveloped and damaged that she could not breathe to sustain herself without extra oxygen. [Chase] [Alyssa's twin brother] was so sick that he needed extra oxygen and a

tracheostomy hooked up to a ventilator. What they call life support in the hospital, we did that here in our living room, so they were very ill, very fragile babies, but we were heavily trained before we were able to take them home so that we could provide a level of medical care in our home instead of in the hospital."(Hope)

Once the child was home, the crisis did not stop. Parents talked about mounting issues and concerns that arose during the first years of their child's life. They found they had frequent doctors' visits.

"…at the beginning we were seeing-- I mean, we were going all the time to specialists…" (Hannah)

The doctors visit during the first year included concerns that are ever present. Zach remembered how his daughter Emily, started having seizures in her first year and the impact that her seizure medications had on her development.

"And when [Emily] was - oh, golly - probably nine months old to a year, somewhere in there, is when we first noticed that she was having seizures. Up to that point, she had the diagnosis of cerebral palsy, but it was more like with her [twin] brother. It wasn't very severe. She had use of her limbs. She had control.

She was actually sitting up on her own. You could hold her by her legs, and she'd hold herself up. Very verbal. Not talking with words but making a lot of different sounds and interacting and stuff. And then when she started having the seizures, my perception is that it wasn't so much the seizures that set her back, it was the medications to treat the seizures." (Zach)

Many of the parents talk about how their newborn's suck and swallow was weak or how their infant coughed and choked when the infant ate. For some, their baby cried all the time. For many of the parents, the baby was not moving their body like they should. Having a newborn can be tiring for all parents, but what happens when you can't blame the continuous crying of the baby on normal issues? What happens when you cannot discern colic from neurological issues? What happens when you begin to see and feel the disability of your child? Josh talked about how his life really began to change towards an authentic reality when he realized that his child's body was different, and that his child needed him. The parents expressed their love of their child; however, they also began to understand that they are unique. The baby cuddles with them, smiles, and tries to look at them. The parents feel love from their baby. The baby, however, has not developed like other babies. Many things are fragile; the baby, relationships, and the parent. Josh spoke about Thomas' fragility in comparison to his younger sibling, Jon.

"So I try to make it really important to teach [Jon] [Thomas' younger brother] that [Thomas] is there. And it's kind of hard but it's a lot different I guess with

having a typical child and having [Thomas] be so fragile like he is." (Josh)

Dan spoke about how choosing a respite provider was difficult and how he could not leave his child alone with the respite provider for very long because of his child's fragility.

"It was very hard at first because, I mean, him being so fragile and we got the respite. And at first, it was just hours at a time because we weren't sure about it." (Dan)

Even through this difficult experience, Josh described how his child's need for him as a father was greater than his own grief or sadness. As Josh described, his child's significant needs empower Josh to think about, care for, and advocate for his child in a new way.

"The movements that he made, his head, he was very rigid with his movements, and I knew it wasn't normal, and it didn't make me sad. It actually made me grow more and more attached to him, seeing that he needed his mom and dad. So we ended up both kind of just accepting the fact that he was probably not going to walk any time soon." (Josh)

Josh also talked about how he guards Thomas, as his protector.

> *"And I baby [Thomas] more than any other child or thing or whatever that I ever have before in my life. And I guess I don't think of it that way. It's just I know [Thomas] is more fragile." (Josh)*

Caring for such a fragile child changed these parents. Some parents described how they were aware that they had lost dreams, identities that they never before contemplated losing; the parent of a competitive athlete, the career minded business-person, the person who places trust in others. Julie and Tricia's stories reflected on the magnitude of how their children's medical issues consume their time and talents, ultimately leading to a new understanding of how their role as parent-advocate truly becomes life and death for the child that they love.

> *"When I went to college, I went for [a professional role] and I'm a [professional], but I think I had a different calling and [Jack] showed me that. I love medical research. [Jack] has multiple diagnoses, and I research and research and research, and I've learned so much about everything medical and that he is. And most of his doctors and nurses ask me if I'm in the medical profession because I speak the language but it's because I had to…" (Julie)*

"[Michael] had a G-tube placed when he was a little over a year old because he just was not able to take in enough nutrition in order to grow the way he needed to, and so they put a G-tube in. About 18 months later to make a long story short, what ended up happening was his G-tube, when it was originally placed it was accidentally placed through a loop of the small bowel which we did not know that and he, at about 18 months of age, developed - at the time we didn't know it was - dumping syndrome, but that's really what was happening, and he developed terrible diarrhea. His G-tube was very loose in his abdomen and leaking a lot. And what had happened was he had grown enough that the tube had popped out of the stomach where it had been originally placed and was laying in the small intestine. [Michael] had been up to about 26 pounds and it was about a 2-month timeframe where he was having these symptoms of not tolerating feeds, and so I had frequent conversation[s] with the doctors. [Michael] continued to lose weight. [He] was very fussy. And long story short, took him to the ER and then they scheduled him for further testing, and we discovered that that is what had actually happened was that when the tube was originally placed the peg tube went through the loop of small intestine and into the stomach, and then as he grew over that 18 months it popped out of the stomach and was in the small intestine. And I had had many conversations with doctors and the office nurses about symptoms he was having and all of the distress. And like I said, [Michael] had gone from about 26 pounds down to about 18 to 20 pounds. So, for him, that was significant weight loss. So, they did

further testing and discovered that that's what had happened. So, because I was trying to be a good advocate for him and tell them something was wrong and they weren't really going out of their way to do a whole lot of testing to see, that kind of changed the way that I typically approach doctors now. I'm a little more demanding in coming to the bottom of things instead of letting things ride and play out." (Tricia)

Julie, in her role as a lifetime advocate and caregiver, contemplated her own future when her son, Jack, will no longer be in school. Julie will no longer be able to stay in her career- understanding that going to school provides a form of respite that allows Julie to practice in her profession, one she really enjoys.

"Stay at home mom is not my dream, but probably is in my future once school is over for [Jack]. I'll be 51 when he graduates. So, my career may be over at 51. Can you even retire at 51? I don't know and I don't want to think about it, it's too far away." (Julie)

Experiencing parenthood through medical fragility requires patience and love. Parents discussed that as they lived forward in time, friendships took a backseat. Josh spoke about how his life and his friendships changed as he re-envisioned his role as a

father. Hope talked about how her priority became the level of quality care that her child needs.

> *"And then nowadays, my friends will tell me-- because I liked a lot of attention back in the day. I was in a band. I won dunk contests, things like that. I fed off of that attention. And then when I had [Thomas], I started changing completely. I don't drink. I don't hang out with my friends because you change. It's like, "Dude, the last thing I'm thinking about is going and wasting money on alcohol and then basically having the flu for the next three days because I'm hungover and I can't even pay attention to my kids [in this hypothetical situation]." I'm like, "That's the last thing on my mind. That's the first thing on you guys' mind. That's all you want to do. You want '[Josh]' to come back out and party with you. That's not me anymore. You guys are on your own there." (Josh)*

> *"With my friends, there was no resentment, but we had to live very isolated early on, so I didn't leave the house for fear of bringing things [i.e. germs, communicable illnesses] back to the kids and we didn't have people over for the same reason, so that led to a little bit more natural pulling away of friendships, but at the same time, I can go back to those friends now and it's like nothing happened. Our lives are very different now, and I feel a little bit more of a drifting away, but any one of my friends, I could call up for, "Hey. Do you want to go to lunch?" and we'd go to lunch tomorrow." (Hope)*

These parents talked about their own individual transformations and how having and caring for a child with severe cerebral palsy changed their life. Josh described how having his child was transformative for him, directing his life towards the person he is today.

> *"the best thing about what [Thomas] has, I guess, done for me. I used to go to the gym, lift weights. I used to be a jock. I used to really care about what other people thought. And I had a huge ego, which I'm still trying to fight. But [Thomas] gave me a higher better purpose than myself, and I could care less what people think. I usually just shave my head because I don't even need to look in the mirror anymore. So, [Thomas], he's changed my insecurity that I used to have too-- I could care less what my friends think. I could care less what parents think. I could care less what other people think of me and [Thomas] when we go out." (Josh)*

The parent is empowered towards a life of acceptance and authenticity. The word authentic comes from the Greek word *authentikos* meaning "original, genuine, principal". Everything in these parents' life with their child is raw and real, however, it can be initially difficult to accept the child's disability. Some parents hold back on getting a wheelchair and stay with a stroller for a long time for convenience, as a way to keep the

physical burden of the wheelchair at bay as long as possible. However, some will also stay with the stroller even after the child is too big for the stroller because of the impact of what a wheelchair can mean: that the child will be like this for the remainder of their life. Julie talked about when she experienced the realness of her child's disability:

> *"A wheelchair made everything real. And so, when we got his first wheelchair, he was five. Well, he was almost five because he started school the day he turned five, and so we needed the wheelchair for school. School needs this in order for him to learn. And we were okay with that, but we didn't want the wheelchair for anything else. We really would have just preferred to leave the wheelchair at school and take him everywhere in a stroller. The wheelchair felt like we were giving up on him ever being able to walk. Because at four, five years old we didn't know. There was still a possibility that he may be able to walk. With enough therapy and enough intervention, maybe he'll be able to walk someday. But when we bought the wheelchair, I didn't want everybody to think, "This is it. We're done trying to walk. He's in the wheelchair forever." I didn't want him labeled in that way. And it's just hard to admit that your child might never walk." (Julie)*

As the child grows, so too does the parents' understanding of their child's needs. The nakedness of reality, uncovered and raw eventually begins to settle in. Julie spoke to how the wheelchair was a symbol that revealed her child's disability to others.

> *"The wheelchair is very hard. Emotionally, the wheelchair is hard. And the wheelchair attracts attention. When we go in public and other people see us with a wheelchair we get looked at. And I know people are thinking, "I wonder what happened? Why is he in there?" So sometimes I wish I just had a sign that said, "This is his diagnosis. This is why he's in a wheelchair," so I can answer your question and you can stop looking and wondering." (Julie)*

The realness of the child's disability evolves into acceptance. If not to help the parent cope, also to obtain the necessary medical, equipment, and financial support to keep their children cared for and to keep their child living in the home. As Julie described, the parent begins to live vulnerably, knowing that there is no ability to hide their child's disability. The daily needs of changing diapers, bathing, lifting, positioning, feeding, coinciding with purposeful listening, loving, and doing this over, and over, and over again, all comes down to the most basic needs that every human requires. The realness of this brings with it an awareness of the authentic needs of all humanity. This revolving interchange of transitory acceptance and re-experiencing and re-ality of their child's daily needs empowers the parent to choose the types of relationships that they will uphold. These relationships, whether with friends or family, medical providers, teachers, or caregivers must be based around authenticity.

The parents talked about the acceptance of their child's differences. They talk about this acceptance as an authentic reality of the needs of their child. This need is not for themselves or their society, but is instead for their child. In reflection of the parent's acceptance, Hannah talked about how she wanted to hang on to her child's ability to use a bottle, not because she wanted to keep Bobby young, but rather so that he could continue to eat orally, any way that he could.

> *"I've gone through five gastro doctors because I haven't liked any of them… So, the first one they found that I actually liked, we were with him for about two years, and then they didn't take our insurance anymore… And then after that I went through quite a few. I just think because I was doing the blended-food diet, and he did stay on a bottle until he was three, which a lot of-- they didn't think that that was appropriate. And I'm like, 'But he can drink from a bottle'… The GIs [gastrointestinal doctors] just didn't think that… His pediatrician never had an issue with it…"[The gastrointestinal doctors thought that] It started to get not appropriate, which I get. It wasn't developmentally appropriate for him to be having a bottle. Fine. But if he's drinking it, he's using his lips. They're building muscle. To me, maybe one day, he'll be able to do more. Why cross that off at that point? And then, when we ended up with the G-tube, I used a nutritionist to come up with a plan as far as his food, what it was going to be. And not all of them [the specialists] were on board with what that looked like."(Hannah)*

Being authentic to the needs of the moment and the realness of their lived experience, parents talked about how they experience situations that require them to cancel activities because of their medical issues. Tricia talked about a last-minute medical crisis in which her family had to miss an important family event.

> *"[Jim's] [Tricia's husband's] niece was getting married. And [Michael] has gone a few times where he has had some increased seizure activity. And sometimes, and especially in the past, I let it ride. And I don't necessarily-- because I hate to give him too much medication. And I like to know what's causing increased seizure activity. I don't want to just throw meds in him just because he's having increased seizure activity. I need to know a reason why. And it was a Saturday, and he started cluster [seizing] that Saturday morning. And we were supposed to leave here at 11:30 to make it up to this family wedding. And it was [Jim's] niece, and they were very, very close. And we struggled with, "Well, do we just take him with us even though he's having these cluster seizures?" I gave him a little extra medicine. They didn't go away. Called the doctor. He said, "Give him a little more." Gave him a little more. They didn't go away."(Tricia)*
>
> *[Researcher: "What were you feeling during that time?"]*
>
> *"Anxiety. Stress. It was terrible. Because here you're so torn. You have a child who, obviously, needs you to be attentive to them and get it figured out. I mean, upset, frustrated with the situation because-- big family wedding. The whole family-- I mean, this isn't a little family. This is a big family ordeal…. And it was*

just really sad because we didn't want to miss the day. But yet, we had to take care of [Michael] I mean, that sounds bad, but I mean, that's reality. So, we all got ready and dressed and took him to the emergency room… Doctor came in. We sat in [the] ER the entire day. Missed the wedding. Missed the wedding. Sat there the entire day. It just kept getting worse and worse. By that evening, I think they sedated him and-- to get him-- because it was just constant seizures." (Tricia)

Parents talked about how their child has taught them how to love authentically. As typical children become less dependent, and siblings grow, their child still has raw needs: to be watched over during times of illness or seizure, to be held during hospital stays, to be worried about out of sight. To fully care for their child, they did not have the time nor energy to return to their prior identity. Josh discussed his transformation in how he saw himself before he had Thomas.

" I would be the guy who would be coaching [Thomas] and bragging about how awesome at football or basketball he was. I would have probably been that guy. Putting it on Facebook, and saying, "Yeah. This is my son. He's blah, blah, blah, blah. Oh yeah, those are the new Jordan's, whatever." And now, I hear moms getting out of cars and talking to their friends, and they're saying, "Oh yeah, this is the new Burberry dress for my two-year-old daughter that she's going to grow out of in two months," and I'm like, "This is what's important to you to tell your

friends?" And after you look in deep to it, you realize that the parents have children to satisfy themselves and meet their own needs. It's like, "You have to go to college because that's what I did. That's what you do. You have to be Christian. Because I worship Jesus, you have to worship Jesus. You have to do this. You have to do that. Everything that you do must satisfy me. I should be able to tell my friends that you're going to be a doctor. That will make me happy. "And that's what parenting is now. And it's hard to escape that. I get it. Because just like I was saying, already in my head before [Thomas] was born, I was thinking, "Oh my gosh. He's going to be the best basketball player in the world. He's going to be so good. I'm going to teach him every day, and he's going to be--" and I had all these ideas to make myself happy. And then once we had [Thomas], it was like, "Well, now, I got to make [Thomas] happy." It's changed completely how you look at everything. And that's why I say, it's the best thing that I had [Thomas]."(Josh)

The parents' relationship with their child is authentic and lifelong. The care needs are intense, but so is the love for their child that is continuously so dependent on the parent. Others' acceptance of their child is one of the most important things to maintain and build new relationships, whether it be with doctors, therapists, or other parents. They find that others must meet them where they are. Others must come to the relationship with some form of empathy to understanding the realness of the parent's existence and priorities. Hope talked about how her children's illness required her to separate herself and her children from others, and how this caused others in her life to drift away.

> *"…for kids like mine who are medically fragile, for [Chase] [Alyssa's twin brother], who was on a ventilator at home, one of the first things your medical professionals tell you is, "Do not have people around your kids who have been around other small children, especially ones who are sick." … "we put a boundary around our kids as recommended by our medical professionals. It had nothing to do with anybody, it was equally enforced… It was sad. So, all of those people kind of drifted away." (Hope)*

The relationships of friends and family that were authentic before are maintained. The friendships that were built on care and understanding live onward. The relationships that were focused on the self-dissolve. This further creates a barrier between the old and the new, the then and the now. Transformation continues.

If authentic relationships already existed prior to the birth of the child, these relationships will rekindle more easily in the future. If the parent had a strong church family before their child was born, this church family surrounds the individual with compassion afterwards. Kim spoke about how her church helps educate others about children with special needs, in some ways to build friendships around her daughter.

"I think it is important to educate. I do. I love what our church is doing with these kids that they get to be around-- because we really don't have any kiddos like her in our church, and we have almost 1,500 people in our church." (Kim)

Friends with compassion are willing to make space for the child's needs in their own home to give the family someplace else to visit, to get away from the home that captures so much of their time and energy. Special needs equipment takes up room and is sometimes clunky and awkward. Getting a wheelchair into a home can be difficult. A friend will make space for the parent and the child in their life. These are the relationships that the parent is drawn to. Relationships that meet the parent where they are. Relationships that are based around authenticity. Hannah talked about her friendships, and how she feels grateful that they appreciate the reality of her and her son's needs, even if those needs are sometimes complex.

"I'm very fortunate that I have a great group of friends that are very understanding and accepting. It's hard sometimes to make sure he's [Hannah's son, Bobby] feeling like he's included in a part of the kids playing. Him not being able to sit unassisted on the ground or run around and play or constantly being in his wheelchair that's above the eye level of kids makes it challenging at times. Of the ways that we do try to include him is a lot of talking and communicating with him." (Hannah)

Theme 4: Living a Life that is Planned, Forced with Structure and without Spontaneity

To care for their children with significant medical and physical challenges, these parents talk about living a life that is planned, scheduled, and without spontaneity. Without this planning and schedule, these children would simply not receive proper care. These parents spoke about how their child has so many needs that require thoughtful and purposeful planning. This is because the child requires around the clock medical care and assistance for all of life's functions.

> *"So public time we have to plan for. So, if we are going to spend a day outside the house, we have to plan for every meal and medication time, and pack that stuff and take it with us. There's always going to be a diaper bag even though he's not a baby. There's still diapers involved. We have to know where we're going and is there going to be a place for us to change his diaper and if there's not, how are we going to deal with that? Do we need to park close, so we can go back to the car and change him in the car if we need to? His eating times. If we're just going out and there's meals, we're pretty good because we can just*

load the feeding bag, do the feeding pump, and it's done. If there's going to be a second meal - if we're going to be out all day - then we have to find a place to wash out the bag. And there's just a lot of other things you have to think about. Then, there's emergency things we have to take with us. He has seizures, so we have a rescue seizure med. That always has to come with us. We have all the diapering supplies. Medication that is due. And then we always carry Tylenol… So it's just that we have to plan so much. There's nothing spontaneous." (Julie)

Mealtimes away from the home always require planning. If the child eats orally and has difficulty swallowing, the parent must pack special equipment to blend food. Some children require special utensils that are soft enough that the child will not bite down and break teeth, but strong enough that it will not break apart and dislodge into the back of his or her throat. If the child is fed through a gastrostomy tube, the parent has to bring along tubes and connectors, bolus syringes, and special formula. If the parent has decided to blend the food that is placed in the gastrostomy tube, the parent has to prepare the food ahead of the trip and place it into a cooler. There is never an opportunity to simply stop and pick up fast food on the way to an activity. Everything must be planned. Tricia and Kelly both spoke about this lack of freedom that they feel, knowing that their children needs this high level of care.

"Just that we don't have as much, maybe, freedom to do things, or anything that we do do has to have a lot more planning to it. We're not quite as spontaneous,

maybe, if you know what I mean. Everything has to be kind of planned out, take everything into consideration, make sure that-- usually, for packing things, it's a lot more work to make sure all the medicines are packed, and all of his formula for his feedings, and making sure that, potentially, where we're going is handicap accessible, and make sure we have the charger for his electric wheelchair. And so just a lot of different things, I think, that make it a little more of a challenge." (Tricia)

"But then there's no freedom to just do things spontaneously. You have to plan every moment because [Bradly] is still in diapers because he doesn't eat anything besides pureed food that I make. So in those ways, there's no spontaneity in anything we do. We have to plan so that I can bring anything we need for him. Obviously, the other things that can be a little challenging are all the equipment you have to bring. [Bradly's] getting too big for the grocery cart, so, now, it's juggling his wheelchair and a cart." (Kelly)

Many parents talk about how, in addition to planning, caring for their child simply takes more time. Many parents talked about periods of time in which they feel rushed. Tasks that are simple for most parents are complex tasks for these parents. Daily activities of intense care are always present and always time consuming. This factor of timing even further impacts the need for constant planning.

"So once we get him in the wheelchair, its winter, we're dealing with the coat, so it takes that much longer to get the coat on. When we leave the house, we have the ramp van. And now its winter, so we have to warm up the car. And then we open the ramp and all the doors and get it cold again. And so, when we put him in the car, we have to tether him down. And [Jake] [Jack's brother] helps me tether in the morning otherwise it'd take me twice as long. So, [Jake] does one side. I do the other." (Julie)

"So now, we use the Hoyer Lift. So, it takes extra time because you got to pump it up, and you lift him out, and set him into bed and change his breeches, lift him back up, take him over, sit him back in the chair. So, it's just a little bit of an extended period of time to get things done. And so, I was kind of feeling a little bit rushed." (Mark)

Parents look for opportunities to travel with their child; however, traveling comes with increased levels of planning that go beyond regular packing and preparation. Julie spoke about how planning for traveling includes being able to find medical care in cases of emergency when they are on the road.

"When we go on vacations as a family, I do research the path. We always drive because flying's hard. I research the path we're taking and the hospitals that are located along the way and which are best for handling kid issues. So, if there

was something that happened, I know which hospitals I could turn to for help. And I'm sure other people don't do that if they're planning their vacations. So, yeah. If we have something planned and [Jack] has a shunt malfunction, and we're in the hospital for a week, then plans get shoved to the side." (Julie)

Planning also includes understanding and planning for the child's unique social, emotional, and sensory needs. Some parents talk about their child's special issue with sensory overload, a type of issue where the child becomes distressed when there is too much activity or noise. This can lead to outbursts from the child or signs of physical discomfort. When this happens, parents often find themselves in a situation that they have to leave an environment to help their child recover or feel better.

"He's very sensitive to noise. So, I can pretty much guarantee he's going to have a meltdown with all the noise. But we try to go prepared with the noise-cancelling headphones and stuff." (Kelly)

"He's like, "Ergh." He just makes this noise where you know he's not happy, and he just fusses and fusses. And then we say, "Do you want to go back to your room?" And he'll just look at us like, "Yes." And so, when we take him back in his room, get him back in his comfy place, then he's happy again… because sometimes he just can't handle that outside environment of loud and people and it's overwhelming to him. We also have noise canceling headphones to help him in an environment that might be difficult." (Julie)

“She just acted like she was tired. She wasn't really sleeping, just totally zoning out. Like, "Just leave me alone." Yeah. Not smiley. And when we first started, during the beginning of the session, she's really excited about it. But then I think it was just way too over-stimulating. "I'm just done." So, she put her head down, and [would] not move, and not really respond. “(Kim)

When a child requires this level of care, planning, consideration, understanding, advocacy, and relational knowingness from the parent, it can be difficult to plan for the child’s future. This concept of never-ending caregiving was expressed in the theme “Life is Hard, Filled with Burden, Worry, and Love”. However, in this current theme, “Living a Life that is Planned, Forced with Structure and without Spontaneity”, we see the magnitude and lifelong need that future caring has created tremendous fear for the future of the child.

“Yeah. There's a lot of giving care I mean, there will be. I mean, that's just a reality. And sometimes that's hard to think about and just know. I mean, I just know that's always going to be there.” (Tricia)

“And the reality is, [Bobby] will require full-time care through adulthood. It does start to give me a little bit of an overwhelming feeling when I start to think

about it, so I always think it's important when dealing with [Bobby] to just take it either one day at a time, one week at a time if I can, one month at a time, or year. When you look too far ahead it gets way more emotional." (Hannah)

In a life built around planning, one of the most important but most difficult things to plan for is their child's future. Many of these parents are fearful for their child's future. Many parents talked about the idea of their child moving to a group home as being one of their greatest fears. Moving to a group home requires trust on the part of the parent, but parents understand that institutions cannot protect the child from individuals who may cause harm. They talked about this fear and where it comes from.

"And fear. Yeah. Well, yeah, because you don't know. I mean, you could take somebody there, and oh, yeah, they'll take you around for a tour. And it's all great, and wonderful, and sunshine, and looks like paradise. But behind the scenes, a whole different story." (Dan)

[Begins with Researcher: "Do you like to think about the future?"]
"No. It scares me."(Kelsey)
[Researcher: "And why does it scare you?"]
"Because he doesn't have any siblings to look out for him if something happened with [Greg] [Kelsey's husband] and I." (Kelsey)

"I don't want him to go to a home because I don't know what's happening at the home. As of now, right now, I don't know. I have no idea what they're doing at night, what goes on, and how good the nurses are, and already I was terrified to take him to school." (Josh)

"Yes. As far as it depends on my husband and I, we do not want to put her anywhere as long as we can take care of her." (Kim)

The looming question that remains is "who is going to treasure this child when the parent is gone?"

Summary:

After the final analysis, four themes arose from the data. (See Figure 4.1: Themes) The themes reflect the lived experience of parents who care for their child with severe cerebral palsy. As established by Max Van Manen, understanding phenomena of human experiences incorporates four existentials including relationality, spatiality, temporality, and corporeality.[132] While each of these themes touch upon each of these four existentials, each theme has prominent existentials that reflect in the process of analysis of the data.

Figure 4.1: Themes

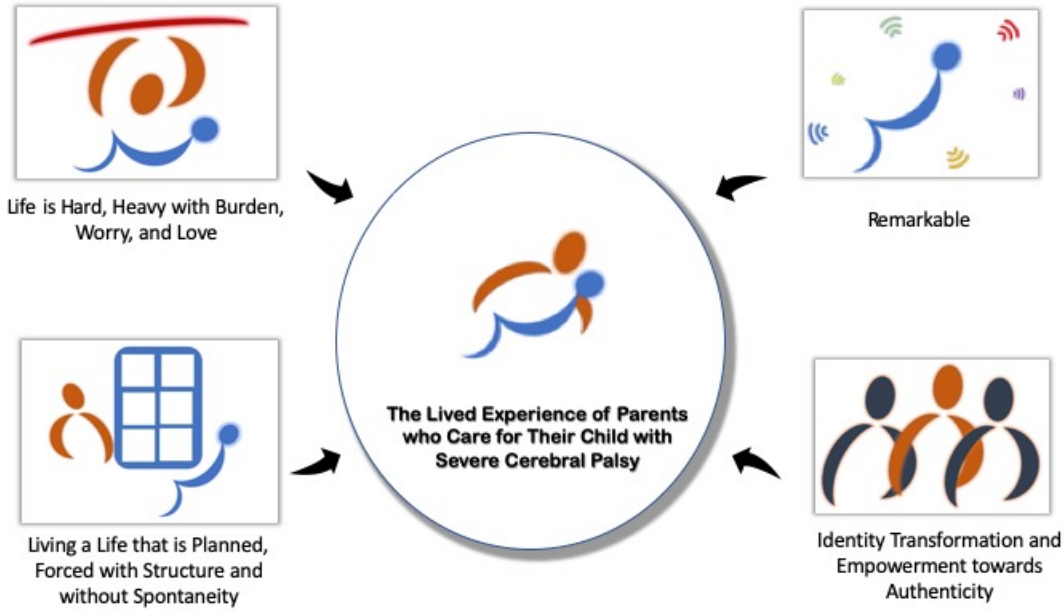
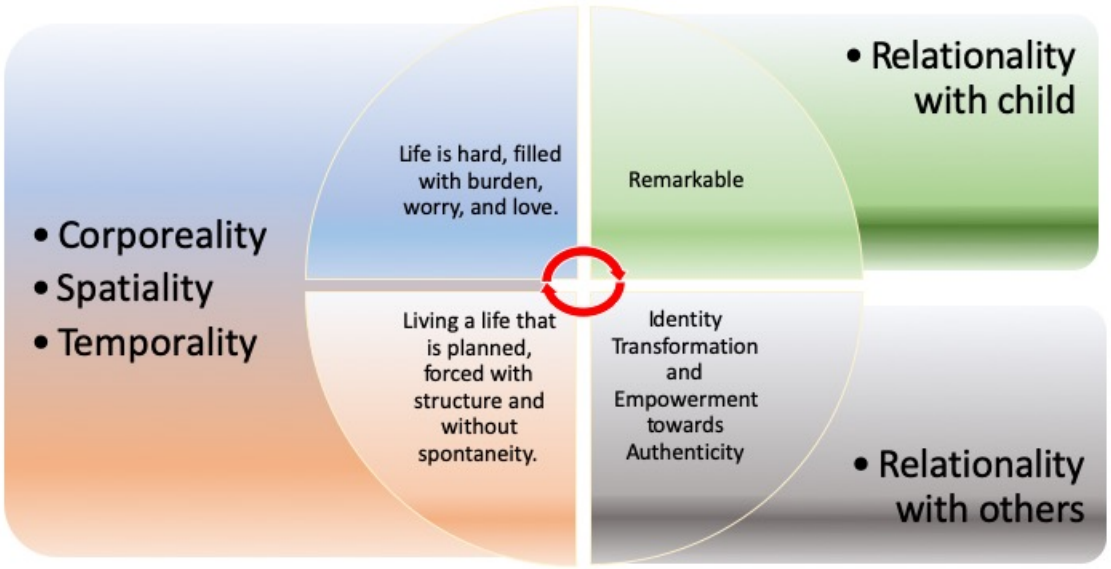


Figure 4.1: This figure represents the 4 themes revealed in the lived experience of parents who care for their child with severe cerebral palsy: (1) Life that is Hard, Heavy with Burden, Worry, and Love, (2) Remarkable, (3) Identity Transformation and Empowerment towards Authenticity, and (4) Living a Life that is Planned, Forced with Structure and without Spontaneity.

The theme “Life is Hard, Heavy with Burden, Worry, and Love” is closely related to concepts of corporeality and spatiality, in which the data was analyzed from the perspective of the participants, their body, and sense of self. From this theme, we see the physical toll that being a parent of a child with severe cerebral palsy has on the individual participant. We also see how the participant’s sense of home is also impacted, where the space in which the participants live is impacted by the magnitude of care that their child requires. The theme “Remarkable” is closely related to concepts of relationality to the child and the bond that is formed between the parent and child as they explore methods of communication and understanding. The theme “Identity Transformation and Empowerment Towards Authenticity” is also closely related to concepts of relationality, however, this theme explores the participant’s relationships with others. Within this theme, a transformation is seen in the context of how impactful caring for a child with this level of severe cerebral palsy is for these parents in their relationships with other people. and the theme “Living a Life that is Planned, Forced with Structure, and without Spontaneity” is closely related to concepts of temporality, in which we see the impact that being a parent of a child with severe cerebral palsy has on the parent’s connection with time, and that feelings of structured planning and lack of spontaneity are essential to the phenomena of being a parent of a child with severe cerebral palsy. (see Figure 4.2: Max Van Manen Existentials and Themes)

Figure 4.2: Max Van Manen Existentials and Themes



Themes in relationship to the 4 Existentials established by Max Van Manen (1997). [132]

Chapter 5: Discussion

Introduction

In this study I describe the lived experience of parents who care for their child with severe cerebral palsy. I gathered data from each participant that included both written and voice recorded journals and in person interviews. The data were analyzed using constant comparison, a thoughtful and iterative process of line-by-line analysis, high-lighted overview, and wholistic examination. These interpretive techniques were then combined to formulate a phenomenological thick description. Chapter 4, Findings, is the result of this phenomenological interpretation. Within the textual information given by the participants, the following themes were discovered in a careful and thorough approach to analyzing the data:

1) Life is hard, heavy with burden, worry, and love. Within this theme parents talked about a very personal yet present amount of heavy load and worry that is involved in the care of their child. They also expressed how the love of their child is integral in their day-to-day commitment and care.

2) Remarkable. This theme speaks to the language that is conveyed between the child and the world around them. The parents observe how the child expresses meaning through body language. Throughout this theme, the data describes the parental understanding and interpretation of their child's lived experiences. This study also examines and interprets how the parents view others as they approach and interact with their child.

3) Identity transformation and empowerment towards authenticity. This theme explores the change that occurs with the parent in their awareness and relationships with others throughout their experience of raising a child with severe cerebral palsy.

4) Living a life that is planned, forced with structure and without spontaneity. This theme explores a consistent message of the parents relationship with time in consideration of the care and lifelong needs of their child.

Within this chapter, I present my discussion and conclusion of each of these themes. I also provide implications from these findings, discuss recommendations for future research, and discuss limitations of this research.

Theme Conclusions

Life is Hard, Heavy with Burden, Worry, and Love

Within this study, many parents talked about their lived experience as parents who care for their child with cerebral palsy. Parents talked about the evolution of their life-story. Most of these individuals began parenthood with copious amounts of medical trauma. Their parenting experience evolved into an ongoing role as protector and caregiver of a fully dependent child with frequent bouts of medical fragility. While taking care of this fragile life, they bond with their child, learning what unconditional love really feels like. With so much to worry about, these parents literally and figuratively carry the heavy load of this child's hardship.

The lived experience of parents who care for their child with severe cerebral palsy is a complicated, dynamic mixture of miraculous love that exists within a domain filled

with medical complexity, daily duty, and limitless care. The parents spend all hours of their day and night caring for their child. Where this differentiates from parenting typical children is in knowing that they are part of a lifelong relationship with their child that is built around love and dependent, continuous need. Unlike parents of neuro-typical children, the physical care for these children is endless.

These parents take their child to many ongoing medical appointments. These parents seek out medical providers that will provide exemplary care for the child and will listen and advocate for the needs of the parent and their child. These parents also seek healthcare providers that will support the parent and the decisions they make for their child. They are willing to travel great distances to get this level of care. Parents seek therapists who are sensitive to the child's need for activity and comfort, and will celebrate with the parent in their child's successes. In the beginning, these parents attended therapy in the hopes that their child would gain more skills. As time passed they fully understood the magnitude of their child's disability. As these parents consider their future and their children's futures, they know that the child that they love so greatly will grow and become, in many ways, a heavier version of the child they see today.

The word burden is sometimes a difficult word to use when describing something that is so important and meaningful. This, in part, is because the word "burden" can potentially be applied to an individual, instead of a task or a situation. With these parents, the child is not the burden, but the child's level of care and the worry that comes from this level of care is a burden that all of these participants experienced. This burden was expressed as both the physical work associated with the care of the child, as well as the emotional burden that each of these parents will carry throughout their lifetime. When

burden is examined in this context, it is revealed that, for these parents, burden exists because of the love that these parents have for their child.

Caregiver burden is not a new concept when it comes to caring for children with cerebral palsy. A study performed by Marron et al[162] showed that for this parent population, as the level of child-related disability increased and caregiver-related depression increased, so to did the magnitude of caregiver burden, as measured by the Zarit Burden Interview.[163,162] A study by Brehaut et al[164] examined the health of parent caregivers of children with cerebral palsy and determined that characteristics associated with the caregiving responsibilities of these parents led to greater physical and psychological issues for the caregiver when compared to the general population of parent caregivers.[164]

The current study revealed many of the physical barriers encountered throughout the parents' daily routine. It also revealed many of the underlying psychological burdens of worry, frustration, and sadness that each of these parents experience. When parents expressed the multiple life impacting medical decisions that needed to be made for their child, these parents anguished over the potential consequences. Medications are prescribed to combat every rendition of health ailment. To keep medical knowledge and appointments straight, many of these parents made home-based medical charts to keep track of this complex medical information; information that many professionals go to school for many years to learn and understand. These parents seem very determined to make the best decisions for their children.

These parents understand that they carry a heavy load of physical and emotional burden. While only a few parents actually used the word burden specifically, all of the parents talked about it in the sense of the heavy load that they bear as parents. However, these parents' burdens are not to be mistaken as a wish for relinquishment. Yes, if a miracle could happen, then many of these parents would take their child's disability away. However, even this was selflessly given to relieve their child from the pain and disability. These parents understand that a burden is a natural part of existence, and while they did not choose their child's condition, their child's hardship is now theirs to carry. While some talk about slowly integrating help in the form of in-home nursing and paid caregivers, all of the parents feel hesitant to do so because of the worry and fear that their child will not be properly cared for.

Many of these parents minimize their burden by focusing on the love and affection they have for their child and their relationship with God. The parents saw their child as being a gift from God, and their spirituality provided them with a divine context to their life situation. This shared sentiment among the parents seemed to be born out of the realness that is required to care for their child. These parents sense that through the care, the worry, love, and concern, that they are closer to their God. In some ways, these parents want so desperately to convey that their children are more human than many, that their children's needs are earthly and real, not wrapped up in the cultural placement of being. However, American culture values paving ones own road through progressive independence. Their child will not reach a state of autonomy and independence. As their child grows and develops, their abilities and appearance will match less and less with those of their peers. As this divergence occurs, the child will begin to look more like an

adult, but will always need the same level of totally dependent care as they did when they were an infant. These parents know that they will always need to protect and advocate for their child to sustain this simple but important proclamation: that their child must always receive care that promotes a life where the child is safe, happy, healthy, and feels loved.

Remarkable

A Need for Time to Listen

One thing is absolutely certain to these parents: Their child is worthy of notice, as human, as being. The way that these children communicate is comparable to the use of analogue signals in a world of digital communication. These children communicate without speaking. Sometimes the things that are shared are difficult, rudimentary, or raw aspects of being. However, parents also talk about communication as being complex and expressive of the child's wants and needs.

This method of conveying ideas and information requires an awareness and tactful sensitivity on the part of the listener. If the listener is interested in understanding the experience of the child, the listener will need to slow down, observe, and understand the child's life experience in time and space. The listener needs to be sensitive to all of these various parameters. The listener needs to spend time with the parent and their child.

Time that is spent with their child helps the parent unravel the complexity of his or her needs and wants. A thought or a feeling can be conveyed through body movements, a sound, or a facial expression. More intense and purposeful messages can be conveyed

through the eyes and the intensity of the looks and sounds from these children. The listener must take these points of information and pontificate on their meaning.

In many of our healthcare environments today, time is money. Time however is what these children need the most: time to allow the healthcare provider to observe, listen, and because of the physical pain that the child may be experiencing, to diagnostically touch the child to better understand their physical problems. When the parent does not sense that a provider is willing to invest this time in their child, the interaction will quickly convey a message that this provider does not care for their child. Sometimes people are not willing to provide the time parents perceive as necessary, essential, or crucial to listen and understand. And even more concerning, sometimes healthcare providers are not willing to accept the information being portrayed as worthy of notice.

The reality is that the time these parents are looking for is not always the same: quality outweighs quantity. What they are often looking for is a provider who will say "Hello" and kneel down to introduce themselves to the child. They are looking for a provider who will observe, investigate, and discuss the concerns of the parent. They are looking for a provider who has as much concern for their child's well-being as they do. Many of these parents have found providers who match these qualities, yet then had to navigate through their local and regional healthcare systems to keep them. Not all providers impart this level of self reflection and awareness. To be able to care, to listen, and to try to understand is a skill that needs to be valued by the individual provider and cultivated within the individual provider's practice over time.

Understanding Pain and Emotional Distress

The participants in this study share a universal concern about their children's pain. They spoke of observing facial expressions, body movements, and the sounds heard through their child's moans and cries to decipher pain from emotional distress. Parents spoke more confidently about being able to decipher the difference between whether their child was experiencing pain or emotional distress. However, distinguishing mild discomfort from emotional distress can be more difficult.

When a parent thinks that their child is having pain, they sometimes find it difficult to determine the type or location of that pain. Using intuition and past experience as a guide, these parents are able to observe squirming movements and consider if this type of movement is due to gastrointestinal pain, constipation, or discomfort from body aches. They observe quicker movements occurring with a grimace or a cry to understand if their child is experiencing muscle spasms. They touch and feel their child's extremities for areas of tightened muscles to sense what the child is trying to tell them. They change their child's position to see if changing the angle of the hips improves their child's responses. They investigate, hypothesize, and act to determine if their assumptions are correct. They employ a form of single subject natural science to help their child in the moment. Sometimes these parents are unable to fully decipher what is happening to their child, in their child. In these moments they may try some Tylenol™ to see if it helps. If the child has a seizure around this time, parents begin to wonder if the sign of discomfort was an aura, or if the seizure was a result of the discomfort that the child was experiencing.

The parents often spoke of emotional distress as being more from frustration, observable by looking at the child's face, or listening to a whine that their child vocalizes. Many parents turn to the child in these moments, running through a mental checklist with the child, asking the child about what could be the problem. At times the parent can determine what the issues is by considering the lived time of their child. They review the past, present, and future happenings of the child to gain insight into what the child is thinking and experiencing.

One thing is for certain to these parents; their child is actively communicating with the world around them. However, this communication is often extremely limited. The more that a provider knows about the life of the child, the better chance that the provider will be able to listen to and understand the physical and psychosocial needs of the child.

Identity Transformation and Empowerment Towards Authenticity

Parenting can be a transformational experience for the identity of any new parent. However, having a child with lifelong significant medical and physical challenges, makes this transformation different. Many of these parents entered into parenthood through an experience of fearful trauma. Often their child is born through medical complications. Sometimes this trauma occurs both to the newborn and the delivering mother. Through this occurrence, these parents experience an approximation of loss that is full of grief. Their child is not taken from them, but instead their child is dealt some of the greatest hardships. In the beginning, these parents are not certain of what those adversities will be. They worry about their child's future.

Experiencing Isolation

As time passes, parents of children with GMFCS Level V cerebral palsy begin to see the degree of disability experienced by child. Their child loses opportunities: opportunities to eat, to sit, play, and run. Their child loses the opportunity to live life on the child's own terms. In so many ways, the parent takes on these losses for the sake of their child. They fullfil the daily routines to provide opportunities to meet their child's wants and needs. They care for their child, making certain that illness or ill feelings are minimized. This level of care often requires isolation from the world and isolation from their previous relationships.

This level of care has been shown to impact parental physical and social well-being, as well as their overall feelings of having freedom and independence. [13] When a child has greater motor impairement combined with cognitive impairment, parents are more likely to experience episodes of isolation and role restriction.[36] Sensory-based bahaviors have also been shown to increase parental experiences of isolation and limit the parents ability to participate in leisure activities in families of children with autism.[165] This study reveals that parents of children with severe cerebral palsy also may experience sensory-based behaviors that can impact the parents ability to participate in leisure activities, leading to episodes of added isolation. In the theme "Living a Life that is Planned, Forced with Structure and without Sponaneity", Kelly experienced this when her son became ovestimulated with noise, sometimes causing them to have to leave activities or compensate by using noise-cancelling headphones.

Concepts of isolation go beyond the experience of leisure activity, and can enter into the work experience of the parent. Parents of children with cerebral palsy are more likely to have lower income, despite their education level.[164, 166] One reason may be the caregiver's lack of available time and opportunity to work because of the high caregiving demands needed to care for their child.[164] This became an important concept in the theme "Identity Transformation and Empowerment Towards Authenticity" because of the significant impact that being able to work has on the parents identity and daily relationships with others.

Experiencing Dependency of a Growing Child

Throughout the parents journey, many aspects of the parents' life go on hold. While this is often experienced during the first year of parenting any child, what happens when that first year turns into the second, third, fourth, fifth, or sixth and their child is still as dependent as when he or she was a newborns? These parents experience something different than typical parenting. These parents know that their child will need this level of care throughout their entire life- both the child's and the parents'. Meeting the needs of a child at this level becomes an experience of returning to what is natural, real, and raw in being. Meeting these needs puts a new spin of the term 'activities of daily living', where without them, daily *living* will cease. The child relies on the parent for sustaining lifes needs, as well as incorporating supportive psychological, social, and emotional factors for enhancing the child's lived experience. These parents do not get to experience the gradual shift towards autonomy that other parents experience. Their child will be dependent and non-autonomous forever.

This reality challenges the parent to consider what is most important in their life. These parents love their child unconditionally. To experience care in a way where the parent is in control of another's experience becomes a big responsibility. These parents take on this responsibility fully because they are the only ones who can do it at this level. They intermix activities of duty- like changing diapers and giving medications, with concepts of care and love to make their life better. This makes activities of duty more meaningful, life sustaining, and life enhancing. This aspect of having responsibility transforms the parents' meaning of caring for another.

Relational Authenticity

The transformation that these parents experience in care brings them to an authentic way of living. The parents cannot hide the fact that their child has this disability. It is apparent by seeing their child's wheelchair. It is apparent in the ongoing medical needs of their child. The parent's accepts this reality, because it is in fact real. They need for others to accept this reality with them. In this, the parent's move closer towards authenticity, living a life that is based around the realness of being human.

This realness of living empowers these parents. As it is said by McGee (2014), "True caring and compassion necessary for healing cannot be contrived. They must be authentic."[167] These parents spend so much of their energy and time compassionately caring for their child with unconditional warmth and love. In this, the parents need these authentic experiences as well. The parents build relationships being empowered by this authentic way of living. They maintain old friendships and create new friendships that are understanding of the life that is lived by them and their families. Friends will understand

the need for isolation during episodes of illness. Friends will make space for the child and their parent in their home. This level of empowerment goes beyond immediate friendships. This spills over into relationships with their extended family and with medical providers. Those who interact with these parents with an attitude of caring and compassion will connect with the existential empowerment of authentically living.

Impact on Marriage

Historically, it has been perceived that having a child with a disability is detrimental to the marriage of parents of children with severe disability.[168] However, research surrounding this question has been inconsistent in methodology and the effect of disability on divorce has been suggested to be much smaller than previously thought.[168,169] In a longitudinal study looking at the different factors affecting divorce, while a larger number of children appears to increase the risk, having a child with a disability does not.[170] Having a child with a developmental disability may impact some parameters of couples relationships including time spent on leisure activities, however, other important factors still remain, including spousal communication and the ability to problems solve important family issues.[169] This study, "Caring for Childen with Severe Cerebral Palsy: The Lived Experience of Parents" did not delve into the realms of various parent-couple satisfaction, however, this concept of spousal communication and ability to problem solve family issues was represented in how these families spoke to their successes in daily care and routine. It was through this authentic lens that these parents were able to accept the shift that took place within all of their relationships, including their own.

Living a Life that is Planned, Forced with Structure and without Spontaneity

The essence of being a caregiver of a child with such specific medical needs is built around daily recurrent experiences; living a life filled with providing scheduled care that is necessary to keep the child alive and well. These parents awake everyday knowing that the many needs that their child has requires thoughtful and purposeful planning. As the child lives life with dependency, the parent must fill the child's day with routine tasks of care. Dressing, bathing, feeding, medicating, moving; these are activities that are always present. These are the activities of structured living that these parents experience.

Activities that are typically thought of as simple and quick become time consuming activities for these parents. The simple task of dressing a child is more complex when the arms will not bend or the child has a bowel movement after you just completed getting them into their chair and ready for the day. For meals, these children often require complete assistance to eat orally or the parent has to regularly provide nutrition through a gastrostomy tube. Either way, this task takes time and must be undertaken at regular intervals to give the child the greatest comfort, to avoid the feelings of hunger or thirst for their child.

Time can never be borrowed. Medications need to be delivered at specific times in order to have their effects at specific times of the day. Seizure medications are timed to limit seizing during heightened times of activity. Spasticity management medications are staged in different quantities to prevent drowsiness during times of the day in which the child needs to be most attentive; yet in sufficient dosages to reduce muscle tightness and

discomfort. Diapers need changed at regular intervals. The child needs to be repositioned to avoid pressure injuries from staying in one position for too long, or to avoid muscles contracting due to being in a constantly flexed sitting posture.

Every aspect of these parent's life is planned in order to care for their child. Even if the parent goes to work, the time that they are there is planned around their child's needs. Medical appointments take precedence over any other planned activities, and these scheduled medical appointments are frequent and never ending. This type of existence, filled with continuous duty, requires preparation, planning, and consistency. The shear need of daily caregiving tasks require consistency, a lack of spontaneity, and carefully planned care.

With all of the planning that is involved in the life of the parent and child, there is one thing that makes it very difficult to plan for, and that is the future. The parent gives so much of their time, love, and daily compassion to provide care for their child. As the parent looks to the future, they are uncertain who they can trust to help them with their child's care when the parent becomes too old, or the work of physical care becomes too daunting and challenging. The parents understand that our society has homes and institutions that are available to care for people like their children; however, the parents are scared for their child. Abuse can happen in any setting. The one environment that they can truly feel like they are protecting their child is in their own home. The news has opened their eyes to the abuses of children and dependent adults. Abuse comes in so many forms including physical, psychological, sexual, and neglect. The parents understand that their child has a very limited voice. Too many people with limited voice become silent victims. In an institution that prides themselves in giving quality care, the

parents understand that abuse can occur at any level; from the institution to the individual caregiver. Even a single incident is too many. These parents do not want to subject their child to this. These parents want to protect their child, as any parent would. This causes worry and fear within the parent about their child's, and their own future.

Discussion

Care and Duty of Care

This research brings enlightenment to the lived experience of the parent who cares for their child with severe cerebral palsy. The data show that there is a deeply intertwined relationship of love, worry, and burden that the parent has for their child. This profusion of emotional concern can best be described using the historical meaning of the word 'care'. The etymology of the word "care" comes from the old English form *caru* meaning *'*sorrow, anxiousness, and grief'.[171] These parents live life managing their child's challenges. All the while, they see this loved one in a state of dependency, unable to scratch an itch, unable to move and be mobile. These parents are concerned about their child's lived reality, their relationships, and their existence as being; intervening in ways that are complex, difficult, and loving. These parents do this to make certain that their child experiences an optimal state of comfort, health, and well-being. This type of concern is sorrow, grief, and anxiousness. This is *care.* These parents look at their daily activities and see them as interactions that if not completed, could cause further distress for their child, impacting their living experience and overall well-being.

The word care is often compounded in the healthcare field to produce titles or teams of people that fulfill a service; a caregiver, a care coordinator, a care team, a primary care doctor, and family-centered care. Within the delivery of healthcare, care is often described in the context of providing the "duty" of care. 'Duty' is defined as "obligatory tasks, conduct, service, or functions that arise[s] from one's position".[172] When reviewing the findings of how these parents provide care for their child, the meaning of being a 'parent caregiver' begins to take shape. These parents do provide a duty of care to their child. Duty of care happens when the parent wakes up in the middle of the night to change a diaper or to reposition their child to avoid pressure injuries. However, the parents actions and experience of caregiving go well beyond the obligation associated with 'duty of care'. 'Duty of care' is always present, however, when this duty of care involves so much emotional love and 'care', how much of it is actual duty, and how much of it is care? The findings of this study indicate that these parents may bring an emotional spirit to the act of caring for their child. This emotional spirit is seen throughout the data, from their concerns over relieving their child's pain, to their concerns of having their child be understood.

Uniquely lived, these parents understand that their child is never going to be independent and never going to build autonomy. These parents understand that their child will need them for as long as the parents is able to keep them. This becomes the burden that these parents bear. Burden is defined as "something that is carried."[173] These parents literally and figuratively carry their child, and plan to carry their child for as long as they physically can. These parents understand something about care and love that is not universally perceived; that not all healthcare providers can provide more than the level of

"duty of care". These parents believe that to help their child continue to have a life filled with well-being, the caregiver needs to bring to the child the same care and respect for person that the parent brings to the child.

When examining the context of 'duty of care' in todays healthcare environment, the question remains, can somebody be obligated to '*worry, have grief, or be anxious*'? Can somebody be obligated to *care?* This very question is what causes distress in those who truly care for their loved ones. This unanswerable question is one reason why it is so difficult for parents to be able to hand over the care of their child to somebody unknown or to an institution.

Conceptualizing Developmental Tact

The data supports the idea that families of children with severe cerebral palsy celebrate tasks that have the potential to be perceived by those who do not know or understand the child's experience as being small, devoid of value, or meaningless. When a 10-year-old child with severe cerebral palsy rolls over, others may consider this to be either a fleeting tasks that does not serve a purpose, or a goal that was already met 2 years ago. However, the data suggests that parents value these skills and these skills represent purposeful movement that brings both comfort to the child and excitement to the parents to promote a life of well-being for their child.

These parents have seen their child grow, and yet through this growth their children continue to struggle with managing and maintaining the coordination and muscle forces

needed to move their body. The repeated acquisition and loss of movement skills impact their current and future abilities to maintain movement of their joints and to be able to move their body. This concern and sensitivity for how these activities, movements, and mobility play an important part in the current and future child becomes a form of developmental tact. Tact is defined as being a form of sensitivity in mental skill and grace when dealing with another person.[174] This developmental tact is often employed by healthcare teams of physical therapists, occupational therapists, and speech language pathologists through therapeutic services. Through a conscious sensitivity, the therapist works to include perceptions of future implications of the plan of care that is established in the present moment. These therapists utilize this developmental tact to look at the current state of the child, and through their current interventions, attempt to impact the future development of the child's body and ability.

While this concept of developmental tact describes the sensitive nature that is employed by therapists when working with a child with severe cerebral palsy, the optimal utilization of interventions to employ this developmental tact can be difficult to quantify. The goals associated with therapy services for children with severe cerebral palsy is vast. However, as Josh discussed in the theme "Life is Hard, Filled with Burden, Worry, and Love", it can be difficult to determine what body impairments, activity limitations, and participation restriction are worth working on in therapy, and what skills can be managed at home. As the data suggests, there are conflicting points of parental view on this topic. In this same theme, Julie spoke of how lucky she feels that insurance has continued to cover these services. This divergence in views may vary because each parent may see the impact of these services differently.

Many things have to be considered when determining how and when therapy services should be provided to a child with severe cerebral palsy. The concept of developmental tact supports the idea that at a minimum, children with this level of mobility related issues needs to have regular assessments of their body systems to determine if their is an optimal time to intervene to maximize the child's outcomes. In the commentary titled "Intensity of Therapy Services: What are the Considerations?" Robert Palisano and Susan Murr support the concept of episodes of care.[175] In addition, they support the idea that many contextual factors impact the decision for frequency and type of therapy services. When considering developmental tact, it is important that therapists look for sensitive time periods that are necessary to address the specific goals and outcomes determined through the process of family centered care.[175]

Building Self-Efficacy in Parental Decision Making and Life Planning

The data support a shift that occurs in how many of these parents think about and use their medical team. Many of the parents spoke about how the experience of having a child with significant medical issues was a difficult experience. They relied heavily on understanding their childs condition from the medical team. Parents also spoke about how their trust in care providers' decision making abilities changed as they experienced problems with past providers. Many of these parents eventually searched for healthcare providers that would help them make good medical decisions for their child.

This transformation from being dependent on others in the care for their child, to becoming an informed caregiver and decision maker demonstrates that many of these parents were able to speak about their level of self-efficacy in the role of being a parent

caregiver. Self-efficacy in parental caregiving has been described as having a feeling of competence in caring for one's own child, and the level of control they experience in this role.[176] This study supports the idea that this level of caregiver self-efficacy is not always an innate attribute to the new parent caregiver. Within the family-centered-care delivery model, physical therapists play an important role in scaffolding self-efficacy in the parent caregivers of children with severe cerebral palsy. Physical therapists can significantly impact the development of parent caregivers' skills and self confidence for managing their child's needs. This process of scaffolding self-efficacy in parents begins early in the child's life, and is necessary to help families transition through their child's different phases of growth, including into adulthood. As the parent becomes more confident in their role, they also can become more confident as a parent-advocate for their child. This level of confidence and control, or self-efficacy, is necessary in order for the parent to become their child's lasting health navigator.

Grief Interchange with Love and Duty of Care

The data in this study supports the idea that parents of children with severe cerebral palsy experience periods of grief. Grief begins with the first medical crisis that often occurs around the birth of the child. However, repeated events and reminders of their child's disability come with milestones that are not met, or as new medical intervention are recommended that might give the child their best life. In the theme "Life is Hard, Heavy with Burden, Worry, and Love", Josh spoke about how finding out that his child had cerebral palsy caused immediate sadness and worry. Mark also spoke about how

making a decision about his child receiving a life altering surgery struck him with fear, worry, and grief. Julie also spoke about the difficult time she had in deciding to accept a wheelchair into the life of their child. All of these events speak to the continuous and reoccurring periods of grief that occur throughout the parents life.

Parents spoke about how the love of their child is unconditional. As the parent experiences each day that is filled with activity, duty, and care, an acceptance also interplays with periods of grief that make their life of caring for their child meaningful, authentic, and with purpose. These activities provide the family with structure. Built within this structure are moments in which the parents are able to control the interactions, love, and care that their child receives. Many of the parents spoke about how relinquishing this to another caregiver is difficult and requires a significant amount of trust in order to assure that their child receives this level of care. The parents ability to perform these tasks, activities, and duty provides the parent with a level of comfort within the worry and fear. Among other things, these activities and duties are potentially a mechanism that assists in controlling the level of the parents' grief.

How to Listen, How to Understand

These parents talk extensively about how their child understands, listens, and communicates with people who are willing to be open to the parent and child. These children often do not communicate with others through modes of textual words; however, through their body language, facial expression, and voice they are able to send a message to those who are willing to listen. For the sake of providing ethical and responsible care,

any person who is not willing to internally accept that these children have thoughts should remove themselves from the care of these children.

Listening to children with severe cerebral palsy requires a level of sensitivity on the part of the listener. Listening is not conventional, and often requires the combination of hearing, observing, feeling, and perceiving. Listening to these children requires the observer to become aware of the child's life experience. Children with severe cerebral palsy have severe motor coordination deficits. This limitation makes it hard to determine whether a movement is a way towards communication, or if that movement is an adjustment of the body for comfort. These children will often utilize tension, facial expressions, and body movements to convey that they are communicating.

Observing body movements and facial expressions also helps to convey emotions and intentions of children with severe cerebral palsy. Many parents talked about how they utilize a cognitive checklist when trying to decipher their child's wants and needs. The caregiver is able to meet the needs of the child by utilizing a checklist of past experiences that garnered results in communication, and by understanding the child's experience in time. Knowing the past, present, and future activities of the child is beneficial for predicting what is on the mind of the child. The experience of the caregiver in spending quality time with these children is likely to be one of the biggest factors in being able to decipher if the child is communicating and the meaning of that communication.

The data suggest that in order to understand whether non-verbal children with severe cerebral palsy are in pain, one must look for facial expressions, grimacing, painful cries and sounds, squirming of the body, and sometimes, tension in the body. Body tension,

however, can be difficult to use as a descriptor for pain on it's own because it can also express emotions of frustration or excitement.

Many studies look at pain and how we rate pain in children who are unable to verbally communicate their pain.[20,69,72] These studies provide exceptional tools to assist with providing identifiable characteristics commonly observed with pain, however, they are not easily implemented in the home environment. In addition, parents significantly rely on intuition and procedural problem solving in order to understand their child's pain. While pain data helps quantify some aspects to understanding pain, the data suggest that parents appear to find greater benefit in eliciting both methods of inductive and deductive reasoning to find probable or true solutions, respectively, to their child's pain. This process of reasoning is similar to what is experienced in physical therapy practice during the process of clinical decision making.[119] Therefore, there may be a benefit to providing resources for new parents who care for their child with severe cerebral palsy in these methods of decision making in order to meet the pain and emotional needs of their child.

Fear of the Future and Establishing Trust

One of the greatest fears that parents have is regarding the future care, health, and well-being of their child. Every parent in this study was uncertain of the future plans for their child. These parents expressed concern when asked about future plans. Parents fear that if they are not the ones caring for their child, their child will not receive care that incorporates the level of worry and concern that the parents bring to the duty of care. The

parents are also afraid that their child is defenseless and is not able to protect themselves from abuse.

The parents in this study talked about how concepts of trust are an important factor in order to let another person care for their child. One consideration when dealing with trust, is how trust is formed. A study that looked at a nationally representative sample suggested that trust is primarily formed on experiences with different groups of people.[177] This study also suggests that trust is generally malleable across the lifespan, and that social environments play a significant role in how people apply generalized trust.[177] In todays environment of on demand news and knowledge, these parents understand the global presentation of abuse and neglect for children and dependent adults with developmental disabilities. This social awareness impacts the trust that these families have in relinquishing this stressful level of care to other people.

This fear expressed by the parent is real and should not be dismissed or ignored. However, establishing trust with caregivers may need to be addressed in order to provide the parent and child with a different outlook on the future. Trust, however, is very difficult to maintain at the institutional level. Trust must occur with individual caregivers in order to allow trust to form between the parent and potential caregiver. Establishing trust is important for the parent and the child. When the parent is unable to trust others in the caregiving capacity, there is the potential that this fear inhibits the child from experiencing new interactions and building new relationships?

A Recipe for a Life of Well-Being: the Main Ingredient is the Ability to Communicate

The data suggests that one of the biggest factors perceived by the parents that impact their child with severe cerebral palsy is the child's ability to communicate. As it was expressed in the theme "Remarkable", the ability to communicate is one of the greatest wishes of these parents. Through the act of communication people are able to express such significant parts of being. Communication is also one of the biggest catalyst for change in human experiences. When an individual has pain, they begin by communicating about their pain to their physician, caregiver, or a loved one. When a person is in need of something that they cannot physically achieve themselves, they often turn to another person in order get what they need. This experience of communication sits at the heart of meeting the wants and needs for these children.

This ability to communicate plays an important role when considering Comfort Theory. Comfort Theory focuses on responding to the needs of patients from a holistic perspective.[115] This theory explains that meeting the holistic need of an individuals physical, psychospiritual, sociocultural, and environment nature is necessary for experiencing a sense of comfort and well-being.[115,178] However, an important aspect to achieve knowing, is through the individuals ability to convey, discuss, and dialogue about these needs. By better understanding the physical, psychospiritual, sociocultural, and environmental needs of these children, we are able to bring the child closer to a life of comfort and well-being.

Implications for Healthcare and Future Research

Influencers of Care

This study provides insight into the lived experience of parents who care for their child with severe cerebral palsy, how these parents discern pain from emotional distress, and those things that parents feel are most important for the child to live a life with comfort and well-being. Healthcare providers, caregivers, teachers, and the public can benefit from understanding these aspects to the life of a parent with severe cerebral palsy in order to provide compassionate care. In addition, understanding the magnitude of these needs can help provide 'proof of need' to those in charge of legislative action for support of people suffering from life disabling conditions.

This study also supports the time that is needed by healthcare providers in order to provide effective and quality healthcare for children with severe cerebral palsy. In many of our healthcare environments today, time is money. This time is often made available at the level of the provider and at the level of the institution. The institution often dictates the amount of time that the healthcare provider has through the scheduling procedures. In addition to patient care, health care providers are required to perform additional duties in order to manage healthcare. The institution plays a major role in the ability of providers to give effective care for this population. By understanding the time required to take care of a complex patient, the institution recognizes the scheduling needs of different populations.

Understanding Pain, Emotional Distress, Wants, and Needs

This study examines the lived experience of parents and the methods that they use for discerning pain from emotional distress, and understanding the wants and needs of their child during daily tasks of caregiving. In conjunction with the ICF model, the data from this study will help shape future research that incorporate a more holistic spectrum of body, activity, and participation related aspect of care to quality of life measures. Communication is a key factor in being able to relate physical, psychospiritual, sociocultural, and environmental factors incorporated in Kolcaba's Theory of Comfort.[99] The findings of this study provide initial constructs of the relationality associated with the many aspects of care for children with severe cerebral palsy. These initial constructs include the importance of being able to observe and analyze the child's body for tensions and intentions, the child's connections with time and space, and the child's relational aspects with other beings in order to promote enhanced levels of activity, participation, and overall well-being. Future research should concentrate on focus groups and questionaires associated with these relational concepts in order to direct caregivers towards the application of understanding and enhancing a more unrestrained level of activity and participation. Because of the complex nature of pain and emotional distress, children with severe cerebral palsy should not be excluded from the growing body of literature associated with the mind body connection, and concepts of central representation of pain. Future research should focus on incorporating a wider breadth of holistic parameters of study when assessing concepts of pain in children with severe cerebral palsy with a greater sensitivity of awareness and responsiveness to the childs overall physical, psychospiritual, socialcultural, and environmental wants and needs.

Additional research should also focus specifically on the complex nature of how parents communicate with their child with severe cerebral palsy, and more precisely, on the struggles associated with this complex mode of communication. Understanding how this population of parents learn about their child's pain, emotional distress, wants, and needs can help future healthcare providers and future parents provide an earlier onset of enhanced caregiving for children with severe cerebral palsy.

Physical Therapists and other Therapeutic Relationships

Physical therapists play a significant role in the care of children with severe cerebral palsy. As discussed in the findings of this research, many children with severe cerebral palsy utilize a very organic method of communication that incorporates changing body movements, posturing, and sounds that reflect the wants and needs of the child. The physical therapists skill of observation and movement analysis combined with their frequent and early interactions with the parent and child produce a situation in which they regularly evaluate the therapeutic needs of the child. While many of these needs are physical in nature, this research brings to light the psychosocial needs of the parent and child. Additionally, this population often has limited access to services that address appropriate psychological needs of the child. Therefore, this research supports further investigation into how physical therapists can incorporate adaptable psychosocial assessments of children with severe forms of cerebral palsy in order to incorporate these needs into related activity and participation goals for the child. This research also supports further investigation into how physical therapists can address the psychosocial and psychospiritual needs of the child by making appropriate referrals to occupational therapists, speech and language pathologists, and counseling and behavioral specialists

who are willing and sensitive to working collaboratively in the care of families of children with severe cerebral palsy.

This study provides a foundation for future education and research in the mind-body relationship that physical therapists undertake in daily practice. This foundation is especially important when an individual is unable to verbally communicate their physical, psychospiritual, sociocultural, and environmental needs. As a part of the healthcare team, physical therapists are often called on to help with understanding the many wants and needs of children with severe cerebral palsy. Physical therapists are charged with understanding what motivates these children, as individuals. Through family centered care, the physical therapist plays an important role in the psychological health of the parent and child. This is because of the physical therapists knowledge of movement, pain, and the way that these are often connected with emotional distress and expressions of want and need. Parents often turn to those healthcare providers who spend time with their child and assist in problem solving the needs of the child and parent. Future research should look at how movement impacts the mind-body relationship in children with severe cerebral palsy, and the role that physical therapists play in this relationship.

Implications on Future Dialogue about Care

This study provides real-life personal experiences that many parents of children with severe cerebral palsy can identify with. This research may establish a starting point for dialogue amongst families, healthcare providers of children with severe cerebral palsy, and legislators in order to work through some of the barriers that these families find related to current and long term care assistance for their children. Focus groups and social

media groups should be considered as a method of research and discussion in order to further the concepts related to the holistic care of these children in current and future healthcare environments.

Limitations

Limitations: Not Everybody's Experience

A limitation of this research is that the parents, while from regionally different locations, may not represent every parent of a child with severe cerebral palsy. As a requirement of this study, these parents have chosen to care for their child in the home environment. Therefore, this study does not represent those parents who have chosen to have their child cared for in an institution setting.

It is clear that the shared experiences from these parents include similar aspects that are relatable to other parents of children with special needs. This is evident in the short essay written by Emily Perl Kinglsey titled "Welcome to Holland." [179] This essay talks about her experience of having a child with down syndrome. In this story, she talks about parenting as a metaphorical trip that is being planned to go to Italy. However, when her plane lands, she quickly realizes that she is not in Italy, but is in fact, in Holland. She talks about how all the other parents talk about how fun it is to be in Italy, and that while Holland is not Italy, it is also a beautiful destination- encouraging the reader to open their eyes to the beauty of "Holland", the metaphorical equivalent of having a child with special needs. While some of the participant experiences express a similar recognition of being in another place than expected, not all experience it the same way. For instance, in a rebuttal titled "The trouble with 'Welcome to Holland'" written by Kristen Groseclose,

she expresses that in her experience as a parent of a child with Smith Kingsmore Syndrome she is often gifted this essay by well-intentioned people.[158] However, in her experience, she feels that the essay "Welcome to Holland" does not entirely capture her experience nor speak to her grief. At times her son suffers physical or emotional pain that is difficult to witness and continuously return to during difficult times in her child's life. What Groseclose finds troubling about "Welcome to Holland" is that in her own words, "it somewhat minimizes the grief we all have felt for our lost dreams." She feels, however, that she has found a quote that best honors the lost dream and the beauty that exists within this life experience.

"My barn having burned down, I can see the moon." - Mizuta Masahide

This poem speaks to the experience that the participants expressed in the themes "Life his Hard, Filled with Burden, Worry, and Love", "Remarkable", "Identity Transformation and Empowerment Towards Authenticity", and "Living a Life that is Planned, Forced with Structure and without Spontaneity". The experience is not easy. It can be filled with repeated hardship and grief. However, the hardship and grief exists within a vision of a remarkable relationship with their child.

Investigator Limitations

A limitation of this study is that each participant was aware of my professional title as a pediatric physical therapist. This has the potential to have impacted the truthfulness of the participants because of their own past experiences with and perceptions of healthcare providers. The topics explored in this study are sensitive, and there is a potential that the participant may have left out details about their experiences. In order to avoid this

limitation, I engaged in prolonged engagement with each participant. I interacted with the participants prior to the interview date and I spent time during the interview approaching the topic in a non-judgemental way. Throughout the interviews, I was able to observe the emotions expressed by these participants which supports that these participants were able to express meaningful components of their lived experience. I was also able to share in their emotions based on my own experiences as a pediatric physical therapist and father. Through these efforts I was able to display skills of active listening and empathy, assisting to facilitate trust. However this remains a potential limitation of this study.

Another limitation of this study is my limited experience as a qualitative researcher. While I have been engaged in this PhD process for 6.5 years, this was my first major qualitative research project. I do have 16 years of experience interviewing families in a physical therapy setting, however, qualitative interviewing in a semi-structured format is different. In addition, I was able to perform a pilot study that allowed me an opportunity to explore the semi-structured interview process as well in order to hone my interview guide for this study. I was also able to incorporate additional methods to strengthen the methodological rigour including performing inquiry audits, and engaging in peer review. I was able to rely on the guidance of my research committee and other qualitative researchers, however, it still remains that this may be a limitation of this study.

Another limitation in this study is the inherent biases that are brought from my own life experiences as a pediatric physical therapists, parent, and human being. In order to limit the impact on these biases I engaged in reflexive journaling practices to gain insight into my thoughts and beliefs about the topic area prior to the implementation of this study. In addition, I performed a pilot study that allowed for me to continously explore

my thoughts and beliefs as I interviewed these participants to further understand and bracket my own biases from the data being analyzed. I was also engaged in inquiry audits and peer review in order to assist in limiting the impact of these biases on this study.

This research brings enlightenment to the lived experience of the parent of a child with severe cerebral palsy. One question that was not directly captured in this study is "What is the lived experience of a child with severe cerebral palsy?" We gain insight into peoples experiences through the use of textual and verbal dialogue that exists in our spoken language. We are severely limited in our ability to answer this question from the minds eye of the child. In this study, the parents lived experience was used to approach those things, emotions, and experiences that have an impact on the life of the child. The parent was used as a conduit because of the parent-child relationship, the attachment that exists, and because of the day by day, hour by hour, and minute by minute interactions that occur. A limitation in this concept of linking relationally to the lived experience of the child, however, is that the child does not live their life from the same framework as the parent. The child does not have the coinciding previously lived experiences that formed prior to their birth, and the important organization and adaptation that occur with these previously lived memories of the parent. The parents' experience of transitioning through their own childhood from dependency, to autonomy and freedom, to parenting a child with special needs has an impact on their overall perceptions of the world in which they live. The parent is able to observe the injustice of the disability itself, and its impact on their child and themselves. This knowledge and experience interacts with the day to day encounters of not only parenthood, but parenthood of a child with intense and significant lifelong needs. This lifeworld view in and of itself creates a lived experience

filled with duality of meaning of give and take, good and bad, love and hate, right and wrong. This personalized lifeworld view interacts with the current lived experience of being a parent of a child with severe cerebral palsy.

However, we should note that while the lived experience of the parent is not the lived experience of the child, the parents lived experience speaks to, advocates for, and interacts with the child's lived experience. As the parent experiences life with their child, their perceptions, attitudes and belief's may more easily interact with and possibly integrate into the child's lived experience because of the lack of other insight from the child's worldview. As the parent advocates for this child, their overall worldview may be as important as the child's because of the advocacy component associated with parenting a child with special needs. The parents insight may actually hold a larger understanding of the child's care, needs, and perceptions. Therefore, by understanding the lived experience of the parent, we have a better chance of understanding the child's lived experience.

Summary

Through this phenomenological study, I was able to engage with the participants in a phenomenological process to gain greater insight and understanding of the lived experience of parents who care for their child with severe cerebral palsy. From these experiences, I was able to capture a rich description of their experiences in caring for their child with severe cerebral palsy. Parents live a life that is hard, heavy with burden worry, and love. They also see their children as remarkable, able to communicate in non-

traditional ways. While living with episodes of grief, they experience a change in idendity that leads them to living authentically. The care that is required for their child forces a life that is scheduled and without spontaneity. These themes help us understand how parents communicate with their child and how quality time is necessary during care in order to understand the child's wants and needs. By understanding the lived experience of these participants, healthcare providers can better understand the needs of these families in order to provide meaningful care for their children.

Appendices

APPENDIX A: PARTICIPANT FLYER

Would you like to be a part of a study

that helps us understand pain and emotional distress in children who have cerebral palsy?

Study Purpose: The purpose of this study is to explore the experience of parents who care for children with severe forms of cerebral palsy to understand their thoughts about their child's pain, distress, and comforts.

Participants: We would like parents of children who have cerebral palsy and are unable to walk to be part of this study.

Time Commitments: 60 to 90 minutes.

What will be Required: You will be asked to participate in an interview with the primary investigator, Jason E. Cook, DPT, PCS. You may also be asked to review part of the final work from this study.

For more information, please contact:

Jason Cook, PT, DPT

Des Moines University

e-mail: Jason.Cook@dmu.edu

Phone: (515) 271-1433

APPENDIX B: PARTICIPANT INFORMED CONSENT

CONSENT TO ACT AS A PARTICIPANT IN A RESEARCH STUDY

TITLE: The Lived Experience of Parents Caring for Children with Severe Cerebral Palsy

This form describes a research project. It has information to help you decide whether or not you wish to participate. Research studies include only people who choose to take part – your participation is completely voluntary. Please discuss any questions you have about the study or about this form with the project staff before deciding to participate.

Who is conducting this study?

This study is being conducted by Dr. Jason E. Cook in the Department of Physical Therapy at Des Moines University.

Why am I invited to participate in this research study?

Parents who have a child with adult cerebral palsy and limited communication skills are invited to participate in this study. These parents will consider themselves to be a primary caregiver for their child.

What is the purpose of this study?

As a pilot participant, you are invited to help us prepare for the main part of this study by participating in an interview similar to the interview we will perform for the main part of

this study. The purpose of this study is to examine the lived experiences of parents who care for their child with severe cerebral palsy. The focus will be on their experiences associated with their child's distress.

What will I be asked to do?

If you agree to participate, you will be asked to:

1) voice record your thoughts about pain and emotional distress in your child with cerebral palsy over a two week time period.
2) keep a voice recorder secure so that it does not get lost or stolen.
3) participate in a recorded interview with the primary investigator, Dr. Jason E. Cook. During this interview Dr. Cook will ask you questions about your experiences, perceptions, ideas, and belief about your child's pain, distress, and destressors.
4) review some questions prior to the interview to help prepare you for thinking about the interview topic.
5) review the transcript of the interview for accuracy
6) possibly review the final themes discovered from this study for confirmation.

If eligible, the total participation time is approximately 2 hours.

What are the possible risks of my participation?

The risks of participating in this study are minimal. However, there are certain risks and discomforts of which you should be aware. The possible risks are:

1) You may get tired or become distressed during the interview. If you become tired or distressed, you can stop the interview and resume when you are ready, or stop the interview completely.

2) There is a rare risk that your confidentiality could be broken. Rare means that we expect less than 1 out of 100 people will encounter this problem. All of the records involving your participation in this study will be kept in locked file cabinets and/or password-protected files. All of the investigators listed on the first page of this form and any additional staff that assist with management of your files are trained in the privacy and confidentiality regulations that govern research.

3) There is a risk that you could lose the voice recorder during the approximately 2 weeks that you are performing self-recorded journal entries. If this happens, your voice recorded journal entry confidentiality could be broken. To avoid this, you will be asked to secure the voice recorder in a secure location, like your home. When you meet with the researcher, they will transfer the data onto a secure device and delete the data from the recorder.

4.) Because this is a research study, it is also possible that there are risks of participation in this study that are not currently known.

What are the possible benefits from taking part in this research study?

You will likely receive no direct benefits from participating in this study.

This research advances our understanding of how parents who care for their children with severe forms of cerebral palsy think about their child's pain and non-pain related stressors. This information is important to physical therapists and other healthcare professionals who provide care for children with severe forms of cerebral palsy.

How will the information I provide be used?

The data you provide will be used by Dr. Jason E. Cook and the research team in the writing of research articles for publication and in presentations at local and national conferences.

What measures will be taken to ensure the confidentiality of the data or to protect my privacy?

Records identifying participants will be kept confidential to the extent allowed by applicable laws and regulations. Records will not be made publicly available. However, federal government regulatory agencies, auditing departments of Des Moines University (DMU), and the DMU Institutional Review Board (a committee that reviews and approves research studies with human subjects) may inspect and/or copy your records for quality assurance and analysis. These records may contain private information.

To ensure confidentiality to the extent permitted by law, the following measures will be taken: 1) all records related to your involvement in this research study will be stored in a locked file cabinet or in password protected computer files, 2) you will be assigned a code number upon entering this study, and this number will replace your name on the forms we use to record the results of your testing, 3) any names you provide during the interview process will be coded upon transcription by replacing names with their relationship to you (i.e. son, daughter, husband) 4) only the researchers listed on the first page of this form and their staff will have access to your research records, and 5) you will not be identified by name in any publication of the research results.

Will I incur any costs from participating or will I be compensated?

You will not have any costs from participating in this study.

What are my rights as a human research participant?

Participating in this study is completely voluntary. You may choose not to take part in the study or to stop participating at any time, for any reason, without penalty or negative consequences. You can skip any questions on the questionnaires that you do not wish to answer.

Choosing to not take part in the study or stopping your participation will have no effect on your current or future relationship with Des Moines University.

Whom can I call if I have questions or problems?

You are encouraged to ask questions at any time during the study.

For further information about the study contact: Dr. Jason E. Cook, Department of Physical Therapy, Des Moines University, 3200 Grand Avenue, Des Moines, IA 50312; Office telephone: 515-271-1433, E-mail: jason.cook@dmu.edu

If you have any questions about the rights of research subjects or research-related injury, please contact the Research Compliance Manager, Office of Research, 209 Ryan Hall, Des Moines University, Des Moines, IA 50312; Office telephone: 515-271-7481, E-mail: IRB@dmu.edu

Consent and Authorization Provisions

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the written informed Consent prior to your participation in the study.

Participant's Name (printed) _____

(Participant's Signature)_____(Date)_____

Certification of Informed Consent

I certify that I have explained the nature and purpose of this research study to the above-named individual(s) and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered and we will always be available to address future questions as they arise.

Printed Name of Person Obtaining Consent _____

Role in Research Study_____

Signature of Person Obtaining Consent_____ Date_____

APPENDIX C: PILOT FLYER

Would you like to be a part of a study that helps us understand pain and distress in children who have cerebral palsy?

Study Purpose: We need participants who would be willing to be a part of the pilot interviewing process. The purpose of this study is to examine the experience of parents who care for children with severe forms of cerebral palsy to understand their thoughts about their child's pain, distress, and comforts.

Participants: We would like parents of children who have cerebral palsy and are unable to walk to be part of this study.

Time Commitments: 60 to 90 minutes.

What will be Required: You will be asked to participate in an interview with the primary investigator, Jason E. Cook, DPT, PCS.

For more information, please contact:

Jason Cook, PT, DPT

Des Moines University
e-mail: Jason.Cook@dmu.edu
Phone: (515) 271-1433

APPENDIX D: PILOT INFORMED CONSENT

CONSENT TO ACT AS A PILOT PARTICIPANT IN A RESEARCH STUDY

TITLE: The Lived Experience of Parents Caring for Children with Severe Cerebral Palsy

This form describes a research project. It has information to help you decide whether or not you wish to participate. Research studies include only people who choose to take part. Your participation is completely voluntary. Please ask any questions you have about the study or about this form with the project staff before deciding to participate.

Who is conducting this study?

This study is being conducted by Dr. Jason E. Cook in the Department of Physical Therapy at Des Moines University. It is being conducted as a part of a PhD Dissertation. The dissertation chair is Melissa Tovin, PT, PhD at Nova Southeastern University.

Why am I invited to participate in this research study?

Parents who have a child with cerebral palsy who are dependent for all of their care and mobility are invited to participate in this study. These parents will consider themselves to be a primary caregiver for their child.

What is the purpose of this study?

The purpose of this study is to examine the lived experience of parents who care for their child with severe cerebral palsy. This study will also focus on the parents perceptions of their child pain, emotional distress, and the meaning of providing care for their child.

What will I be asked to do?

If you agree to participate, you will be asked to:

1) voice record your thoughts about pain and emotional distress in your child with cerebral palsy over a two week time period.
2) keep a voice recorder secure so that it does not get lost or stolen.
3) participate in a recorded interview with the primary investigator, Dr. Jason E. Cook. During this interview Dr. Cook will ask you questions about your experiences, perceptions, ideas, and belief about your child's pain, distress, and destressors.
4) review some questions prior to the interview to help prepare you for thinking about the interview topic.
5) review the transcript of the interview for accuracy
6) possibly review the final themes discovered from this study for confirmation.

If eligible, the total participation time is approximately 2 hours.

What are the possible risks of my participation?

The risks of participating in this study are minimal. However, there are certain risks and discomforts of which you should be aware. The possible risks are:

1) You may get tired or become distressed during the interview. If you become tired or distressed, you can stop the interview and resume when you are ready, or stop the interview completely.

2) There is a rare risk that your confidentiality could be broken. Rare means that we expect less than 1 out of 100 people will encounter this problem. All of the records involving your participation in this study will be kept in locked file cabinets and/or password-protected files. All of the investigators listed on the first page of this form and any additional staff that assist with management of your files are trained in the privacy and confidentiality regulations that govern research.

3) There is a risk that you could lose the voice recorder during the approximately 2 weeks that you are performing self-recorded journal entries. If this happens, your voice recorded journal entry confidentiality could be broken. To avoid this, you will be asked to secure the voice recorder in a secure location, like your home. When you meet with the researcher, they will transfer the data onto a secure device and delete the data from the recorder.

4.) Because this is a research study, it is also possible that there are risks of participation in this study that are not currently known.

What are the possible benefits from taking part in this research study?

You will likely not receive any direct benefits from participating in this study.

This research may advance our understanding of how parents who care for their children with severe forms of cerebral palsy think about their child's pain and non-pain related emotional stressors. In addition, this research may advance our knowledge of the meaning of caring for a child with severe cerebral palsy. This information is important to

physical therapists and other healthcare professionals who provide care for children with severe forms of cerebral palsy.

How will the information I provide be used?

The data you provide will be used by Dr. Jason E. Cook and the research team in the process of preparing for applying this study to a population of parents who have children with severe cerebral palsy between the ages of 4 and 18 years of age.

What measures will be taken to ensure the confidentiality of the data or to protect my privacy?

Records identifying participants will be kept confidential to the extent allowed by applicable laws and regulations. Records will not be made publicly available. However, federal government regulatory agencies, auditing departments of Des Moines University (DMU), and the DMU Institutional Review Board (a committee that reviews and approves research studies with human subjects) may inspect and/or copy your records for quality assurance and analysis. These records may contain private information.

To ensure confidentiality to the extent permitted by law, the following measures will be taken: 1) all records related to your involvement in this research study will be stored in a locked file cabinet or in password protected computer files, 2) you will be assigned a code number upon entering this study, and this number will replace your name on the forms we use to record the results of your testing, 3) any names you provide during the interview process will be coded upon transcription by replacing names with their relationship to you (i.e. son, daughter, husband) 4) only the researchers listed on the first

page of this form and their staff will have access to your research records, and 5) you will not be identified by name in any publication of the research results.

Will I incur any costs from participating or will I be compensated?

You will have minimal costs from participating in this study. These costs might include transportation costs including mileage, parking, or the cost of public transportation to meet with the primary researcher during the study period.

What are my rights as a human research participant?

Participating in this study is completely voluntary. You may choose not to take part in the study or to stop participating at any time, for any reason, without penalty or negative consequences.

Choosing to not take part in the study or stopping your participation will have no effect on your current or future relationship with Des Moines University.

Whom can I call if I have questions or problems?

You are encouraged to ask questions at any time during the study.

For further information about the study contact: Dr. Jason E. Cook, Department of Physical Therapy, Des Moines University, 3200 Grand Avenue, Des Moines, IA 50312; Office telephone: 515-271-1433, E-mail: jason.cook@dmu.edu

If you have any questions about the rights of research subjects or research-related injury, please contact the Research Compliance Manager, Office of Research, 209 Ryan Hall, Des Moines University, Des Moines, IA 50312; Office telephone: 515-271-7481, E-mail: IRB@dmu.edu

Consent and Authorization Provisions

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the written informed Consent prior to your participation in the study.

Participant's Name (printed) _____

(Participant's Signature)_____(Date)_____

Certification of Informed Consent

I certify that I have explained the nature and purpose of this research study to the above-named individual(s) and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered and we will always be available to address future questions as they arise.

Printed Name of Person Obtaining Consent _____

Role in Research Study_____

Signature of Person Obtaining Consent_____ Date_____

APPENDIX E: Interview Guide

1) *What is the lived experience of parent when they care for their child with severe cerebral palsy?*
    a. Tell me about a time that defines you as being a parent of a child with exceptional needs.
2) *What are the parent's understandings and beliefs about pain and non-pain related emotional distress?*
    a. tell me about a typical day for you as a parent of a child with CP in your role as a caregiver/parent of a child with special needs, describe the activities that you perform in caring for your child
3) *What is the meaning of caring, providing care, and providing comfort to a child with severe cerebral palsy?*
    a. What does being a parent of a a child with cerebral palsy mean to you?

- Consider who, what, when, where, how, and why as follow up questions.
- Consider aspects releated to lived space, lived time, lived body, and lived other (relationality)
- Prompts: Can you give me examples; Could you tell me what I might see or observe if I were watching

APPENDIX F: PARTICIPANT IDENTIFICATION KEY

	Participant Name	**Participant Number**
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